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ABSTRACT

The treatment and care of the mentally ill and developmentally disabled is now and has been the subject of volatile public debate. This paper is the result of an attempt by the Illinois Department of Mental Health and Developmental Disabilities to reorient public focus to concentrate on the major issues involved in delivering effective treatment and care. The department felt that if its motives, policies, plans, and actions were laid out and examined in a rational context, mental health participants in Illinois might join with the department in addressing, positively, the development and delivery of the most effective service. The paper is a description and an examination of the status of mental health and developmental disabilities in Illinois. It is not a plan for action, nor does it contain recommendations. (Author/PC)

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MENTAL HEALTH AND DEVELOPMENTAL DISABILITIES IN ILLINOIS

AN EXAMINATION

by James F. Ragan, Jr.

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November 1974

STATE OF ILLINOIS

Department of Mental Health and Developmental Disabilities
LeRoy P. Levitt, M.D., Director

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PREFACE

In January, 1974, Governor Dan Walker encouraged the Department of Mental Health and Developmental Disabilities to develop this "White Paper". In the throes of rapid social and economic changes, there are always distortions and misinterpretations of the missions and goals of a governmental agency. The field of mental disabilities is clearly an area that does arouse much public response and concern.

This document is the first attempt to formally communicate the issues to the public and to serve as a baseline in measuring the progress of this important state agency. This examination will be followed shortly by submission to the Governor, the Legislature and the public of the Department's Five Year Plan. This Plan was mandated recently by the General Assembly.

It is hoped that this paper will be a further bridge to more significant community involvement and acceptance of the participatory role that all sectors must play if our mental health care delivery system is to function adequately for all citizens in Illinois.

LeRoy P. Levitt, M.D.
Director, Department of Mental Health
and Developmental Disabilities

3/4

TABLE OF CONTENTS

Page

PREFACE iii
INTRODUCTION ix

CHAPTER ONE: ILLINOIS IN PERSPECTIVE 1

A. The Nation 1

B. Illinois 2

C. Other States 6

D. Where Does Illinois Stand? 6

CHAPTER TWO: THE DIRECTION OF MENTAL HEALTH AND DEVELOPMENTAL DISABILITIES IN ILLINOIS 13

A. Goal and Policies 13

1. The Goal 13
2. The Policies 17

B. Analysis of the Goal and Policies 17

1. Criticism of the Goal 18
2. Criticism of the Policy to Offer Comprehensive and Coordinated Mental Health and Developmental Disability Services 22
3. Criticism of the Policy to Guarantee the Major Costs of Treatment in the Community for the Person Most in Need 24
4. Questioning of the Policy that State Institutions will be Integral Parts of Community Delivery Systems 24
5. Concern About the Policy That Communities Should Be Responsible for Planning Their Delivery Systems 27
6. Concern About the Policy That Community-Based Programs Should Be at Least as Good as the State-Operated Programs They Are Replacing 27
7. Concern About the Policy That, in Operating its O.. Programs, the Department Must Provide the Most Effective Treatment and Care 28
8. Concern About the Policy of Transferring Patients to Long-Term Care Facilities 32

C. The Roles of Mental Health Participants 34

Page

CHAPTER THREE: COMPREHENSIVE DELIVERY SYSTEMS OF LINKED SERVICES 37

A. Mental Health Delivery System 37

B. Developmental Disability Delivery System 42

CHAPTER FOUR: PROBLEMS OF SPECIAL POPULATIONS 47

A. Children 47

B. The Elderly 49

C. The Forensic Client 51

CHAPTER FIVE: MENTAL HEALTH AND DEVELOPMENTAL DISABILITY PLANNING IN ILLINOIS 53

A. The Current State of Planning 53

B. A Prototype Planning Model 54

C. Organizational Requirements for Planning 56

CHAPTER SIX: SUMMARY 59

REFERENCES 61

LIST OF CHARTS

		Page
I-1	Expenditures of Department of Mental Health, 1969-1975	4
I-2	Population History of Patients in Illinois, 1960-1973	5
I-3	Mental Health Populations and Finances in Illinois, the U.S., and Other States	7
I-4	Local Public Support for Mental Health Services	9
I-5	Local Public Support for Mental Health Services, Region 2	10
II-1	Planning Areas in Illinois	15
II-2	Planning Areas in Illinois, Region 2	16
II-3	Staff/Inpatient Relationships, FY 1970-1973	29
II-4	Role Matrix	35
III-1	DMH Goal of Comprehensive Delivery System of Linked Mental Health Services	38
III-2	DMH Goal of Comprehensive Delivery System of Linked Developmental Disabilities Services	43
V-1	Prototype Planning Model, Mental Health and Developmental Disabilities	55

INTRODUCTION

The treatment and care of the mentally ill and developmentally disabled in Illinois is now and in the recent past the subject of volatile public debate. Vocal interests are challenging the motives, policies, plans, and actions of a dominant institution in the state: the Department of Mental Health and Developmental Disabilities.

In early 1974 the Department decided that it had to try to reorient the public's focus to concentrate on the major issues involved in delivering effective treatment and care. It felt that were its motives, policies, plans, and actions laid out and examined in a rational context, mental health participants in Illinois might join with the Department in addressing positively the development and delivery of the most effective service. This paper is the result.

In pursuing the examination the author interviewed over fifty people: legislators, Department employees, other state agencies, community board members, service providers, interest groups. He reviewed the literature: relevant research in the field, position papers, correspondence, evaluations and analyses, and statistics. He visited state institutions.

The paper is a description and an examination of the status of mental health and developmental disabilities in Illinois. It is not an expose. While intended to be comprehensive, some may argue that it is not. Some issues may not be addressed. The intent was to focus on the major issues of concern to the citizens of the state. Some issues may be examined too simplistically or incompletely. The observations are, however, a beginning for more intensive analysis. One conclusion obvious to most readers will be that no criticism is totally valid or invalid. Incidents and statistics can be justifiably interpreted in a variety of ways, depending on who the interpreter is. *The paper is not a plan for action; it contains no recommendations.* Necessary changes must come from the participants themselves. Thus, this paper can be used as a starting point for building an agenda leading to the more effective delivery of mental health and developmental disability services. It is the first and not the last word.

The paper contains six chapters.

Chapter One examines mental health and developmental disabilities in Illinois in comparison to national and other state developments and trends. Illinois must be viewed in proper perspective.

Chapter Two closely examines the Department goal and policies for service delivery in relation to the criticisms and problems that have been articulated.

Chapter Three presents and examines the delivery systems of linked mental health and developmental disability services that are frequently discussed.

Chapter Four examines special problems of effective treatment and care for children, the elderly, and clients referred by the criminal justice system.

Chapter Five looks at the purposes, status, and systems for ***planning*** the delivery of needed services.

Chapter Six summarizes the results of the examination, highlighting some conclusions as to why mental health in Illinois today is the subject of so much controversy.

CHAPTER ONE: ILLINOIS IN PERSPECTIVE

The modern era of mental health, involving the active treatment and attempted cure of mentally ill persons, is but thirty years old. The seeds of change were planted during World War II. Prior to that time, mentally ill were primarily cared for in state institutions that emphasized custody rather than treatment. These institutions were isolated from their communities, and their populations grew because communities traditionally wanted to separate the mentally ill from other citizens.

World War II presented a problem of crisis proportions: the hundreds of thousands of soldiers mentally affected by battle and draftees rejected for psychiatric reasons. Psychiatrists had to test and try new methods to deal with this crisis. Veterans' Administration hospitals housed many returning soldiers with mental problems, and the hospitals became training grounds for psychiatrists, physicians, nurses, psychologists, social workers, and other health personnel. The World War II experience awakened mental health professionals to the realization that the mentally ill could be treated effectively and, in most cases, helped to a normalized life style.

This realization was accompanied by two other events: numerous public exposes of the deplorable conditions in psychiatric institutions and the freeing of Federal dollars for domestic programs.

A. THE NATION

The change in the delivery of mental health care began in 1946, with the enactment of the National Mental Health Act to provide training grants for mental health manpower, grants-in-aid to the states for community mental health clinics, and research into the cause, diagnosis, and treatment of mental disorders. *For almost thirty years it has been national policy to test and develop effective alternatives to care and treatment of the mentally ill in large, isolated institutions.*

By the early 1950's, the concept of treating mental illness in the community had gained some acceptance. Government officials and many professionals no longer believed that large custodial institutions could deal effectively with mental illness. One evaluator has called this conclusion one of the best documented finds in psychiatric research.[1]

The transition to community-based treatment and care was facilitated by the introduction of tranquilizing (psychotropic) medications in the mid-1950's. Abnormal behavior causing a patient's extrusion from the community could be arrested by medication, permitting community-based therapies. More patients could be discharged to their communities earlier, with the resultant demand for local programs to treat them.

The U.S. Congress responded to this demand with the Mental Retardation Facilities and Community Mental Health Centers Construction Act in 1963, authorizing Federal grants for the construction of community-based facilities. The Act was amended two years later, authorizing staffing grants to help implement center services. The Federal goal was to support the development of 2,000 comprehensive community mental health centers by 1980. Today there are 546 such centers in the United States (453 are fully operational). It is clear that the goal will not be achieved.

From 1965 to the early 1970's, the Federal Government continued its encouragement of community-based care by authorizing grants for preventing, controlling, and treating drug abuse and alcoholism – primarily in the community.

The transition to community facilities did not occur solely because of Federal Government initiatives. State and local governments substantially increased their financial support for community programs. Health insurers modified their psychiatric coverage to permit more people to obtain some services closer to home. The Medicare and Medicaid programs were implemented to include mental health care benefits for the aged and the poor.

The results have been startling. From 1955 to 1969, the number of mental illness patient care episodes[2] increased from 1.7 to 3.7 million. In 1955 almost half were in state and county mental institutions. Fifteen years later, *only one-fifth* were in these institutions. Outpatient psychiatric services[3] increased from 23 percent of all patient care episodes in 1955 to more than 45 percent in 1969.[4]

Over the ten-year period from 1961 to 1970, the number of resident patients in state and county mental institutions decreased 36 percent from 527,000 to 338,000. More significantly, the number of resident patients per 100,000 population decreased 43 percent.[5]

In 1968, it was estimated that Americans spent $4 billion for mental illness prevention and treatment: 25 percent by the Federal Government, 42 percent by state and local governments, and 33 percent by the private sector.[6] More than three-fourths of the amount spent by state and local governments went to services in state and county mental institutions.[7] *While the national trend has been a significant transition from treatment and care in large mental institutions to community facilities, the largest expenditure remains for services in these public institutions.*

B. ILLINOIS

In 1959, there were 49,000 resident patients in State of Illinois mental institutions, representing approximately 10 percent of the national total. In mid-1974 these institutions had 15,200 residents, a reduction of 69 percent.[8] This figure is slightly less than 5 percent of the national resident total – which can be compared to Illinois 5-percent share of the total U.S. population. State-aided or -operated outpatient psychiatric services accounted for 63 percent of all state patient care episodes in 1973 - 1974, significantly higher than the proportion nation-wide (45 percent in 1969).[9]

What happened? The change began in 1960, when the citizens of Illinois approved a $150-million bond issue: $100 million was allocated to the physical modernization of the existing state mental institutions, and $50 million went for a new approach – the construction of a series of community-centered mental hospital-clinics offering a full range of psychiatric treatment services. Called zone centers, seven were constructed by 1966 to be the crucial link between the community and the state hospitals.

In 1961, the Illinois Legislature created the Department of Mental Health, and the transition from treatment and care in state mental institutions to community-based facilities began. The Legislature greatly facilitated this change. In 1961 it enacted SB 377 which permits counties to tax their citizens to provide facilities and services for mentally deficient persons who are not eligible to participate in any programs under Article 14 (Handicapped Children) of the School Code. Seven counties have so opted, and they annually provide over $400,000 for these programs. In 1963 it passed the Community Mental Health Act, popularly known as HB 708. The Act permits counties, townships, and municipalities to hold referenda authorizing local tax funds for community mental health and mental retardation programs. To date, 37 of Illinois' 102 counties and 11 townships or municipalities have set up community mental health boards to administer these programs. Collectively, these communities provide over $5 million annually for mental health and mental retardation services.

In 1969 the Legislature passed SB 553, which permits counties with public health departments established by referendum to tax their residents for mental health services. Thirty-six counties currently have mental health programs run by public health departments. Almost $1.5 million is provided annually under the SB 553 legislation.

In addition, several townships and municipalities have contributed local tax monies from general revenue (and from Federal revenue sharing) for mental health services. Chicago has done so since 1959.

Of the 546 comprehensive community mental health centers funded under Federal law,[10] 19 in Illinois have received construction and/or staffing grants. Federal expenditures for staffing these facilities in FY 1974 were $4.2 million, with an additional $2.8 million from the state. Federal funds allocated in FY 1975 for children's programs in three centers total almost $700,000. Through FY 1974 the Federal Government had allocated $10.9 million for construction grants to fifteen facilities. The state spent an additional $2.7 million for their construction.[11]

STATE FINANCING

Despite these many initiatives by the Federal and local government units to fund mental health services in the community, in 1973 the State of Illinois funded 80 percent of publicly provided community-based services. The mechanisms are state grants to community clinics and purchase of care from private service providers for mental illness, developmental disabilities, alcoholism and drug abuse. In 1960-61, $6.3 million in grants-in-aid and purchase care were provided, representing 3 percent of total expenditures by the Department of Mental Health. For 1974-75, $67.2 million are budgeted – 14 percent of total Department expenditures. From FY 1960 to FY 1975, total Department annual expenditures more than tripled. Grants and purchase care increased over 1,400 percent![12] Grants and purchase care are provided according to the Department's determination of need. No local matching funds are required. Chart I-1 compares these financial changes.

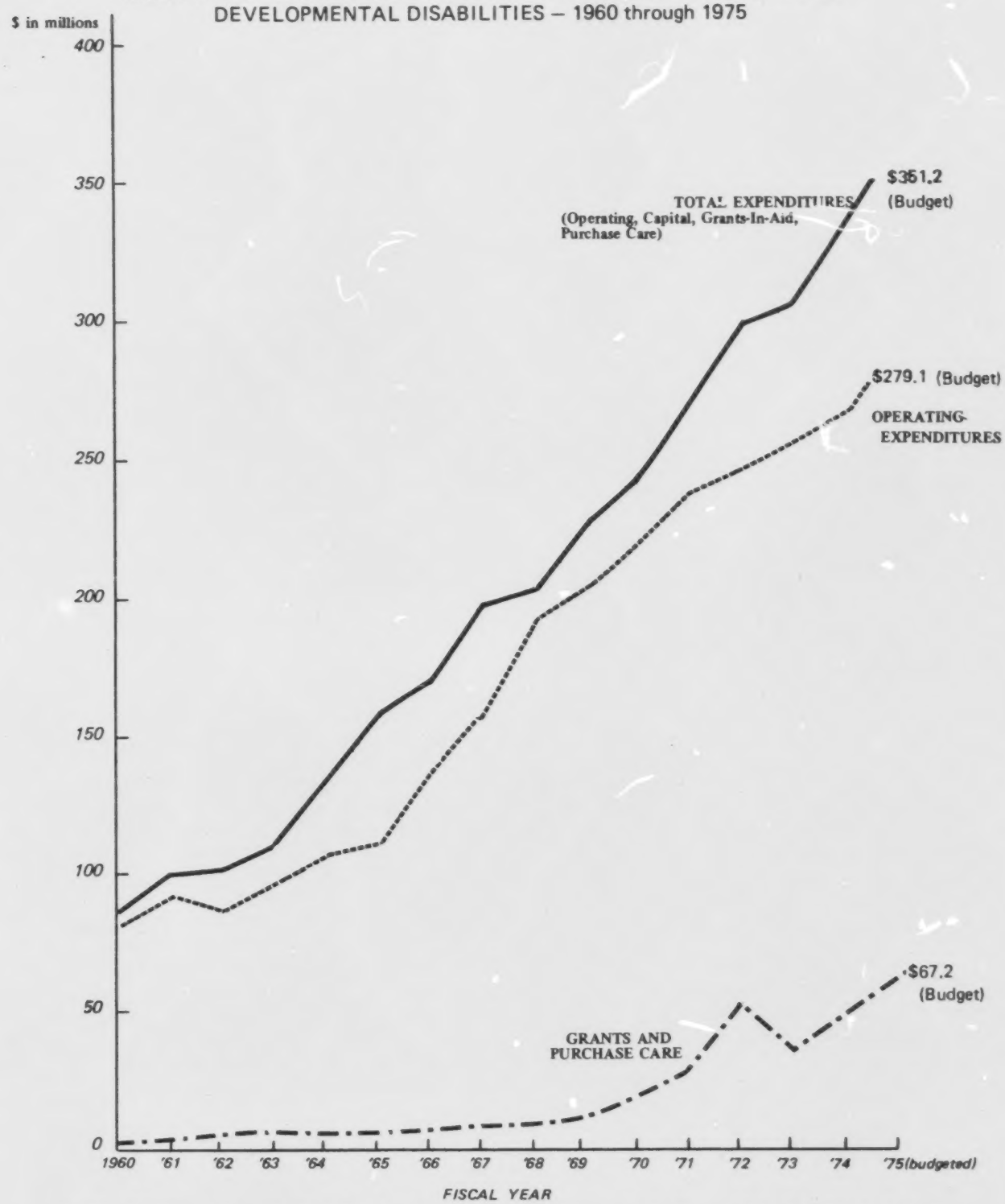
Even more impressive, however, is the Department's shift in the use of its institutions from providing almost exclusively inpatient services to offering outpatient psychiatric services. From 1963 to 1973, inpatient expenditures increased two-and-one-half times. Expenditures for outpatient services were multipled by twenty-five.[13] *While the shift has been significant, the chart demonstrates that Illinois mental health remains fiscally dominated by inpatient treatment and care in its 27 institutions.*

PATIENT POPULATIONS

When Illinois mental health is viewed in terms of patient populations, however, the emphasis is far different. In June 1973, there were 84,500 active patient cases in outpatient clinics supported by state grants-in-aid, and another 29,500 active cases in state-operated outpatient clinics. The resident population on the books in state mental institutions was 15,200, although total resident admissions were 25,700.[14] Chart I-2 displays the population history of these patients over the 1960-1973 period. When compared with the public expenditure history (Chart I-1), it appears that the money has not followed the patients. Several organizations have criticized the Department for these apparently contradictory patterns, a matter which will be addressed more fully in Chapter Two.

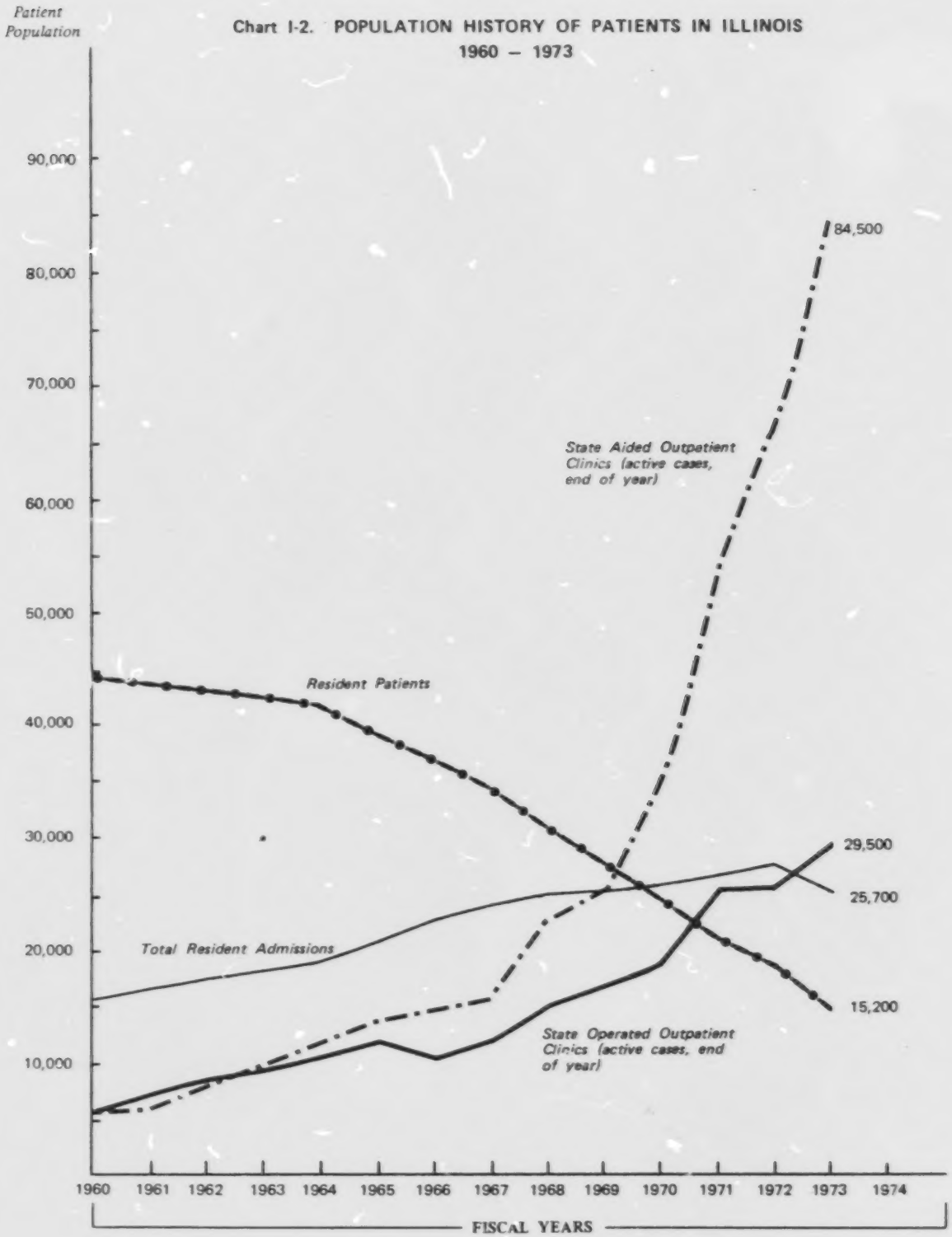
Mental health in Illinois appears to be following the national policy of moving from institutional to community-based care.

Chart I-1: EXPENDITURES OF DEPARTMENT OF MENTAL HEALTH AND DEVELOPMENTAL DISABILITIES – 1960 through 1975



NOTE: In 1973, approximately $30,000,000 in appropriations, formerly coming under Grants and Purchase Care for Public Aid recipient cases monitored by Department of Mental Health, was transferred to the Public Aid Department.

Chart I-2. POPULATION HISTORY OF PATIENTS IN ILLINOIS
1960 – 1973



C. OTHER STATES

Having looked at national trends and mental health in Illinois, it would be useful to look at the programs of selected other states to see how well Illinois compares. (The states were chosen entirely on the basis of available, comparable data.) This subsection summarizes the state/local relationships for delivering mental health services. Population and financial data will be compared in subsection D.

CALIFORNIA — Within the past year, mental health in California has received national attention – both positively, because its state-local arrangements seemed to be working well – and negatively, because the order to close many state institutions was rescinded. In 1969 California initiated a "single system" of state/local mental health care. It provides for a 90-percent state/10-percent local sharing of all mental health services, including care in state hospitals. The local unit of government is the county, and all counties exceeding 100,000 population *must establish* countywide community mental health programs. By 1971 all but two of California's fifty-eight counties had developed a program.[15]

NEW YORK — New York delivers mental health services both through its twenty-nine hospitals and its community clinics. Under its Community Mental Health Services Act (the first in the country), all New York counties have established community mental health boards. These boards are county agencies, and all state funds to communities for operating and capital expenditures pass through them. The state reimburses communities for one-half their operating expenses of approved programs in all counties exceeding 200,000 in population – and reimburses more than one-half for smaller counties. The state also provides one-third grants-in-aid for construction. In addition, through the State Housing Finance Agency, local private nonprofit organizations may obtain low- interest, forty-year loans for construction. Patients in state hospitals, their spouses, and their parents are liable for the full cost of care, or some portion thereof, based on ability to pay.[16]

KENTUCKY — Kentucky has four state mental hospitals, each of which serves one or more of fifteen multicounty regions. Each hospital is divided into geographical units, and each serves a specific area of the region. Each region has a board that operates comprehensive care centers. All patients requiring admission to state hospitals, except those committed through the courts, *must be referred* by a center. The state may fund up to one-half the operating expenses of community programs approved by the boards. Grant funds are not available for capital expenditures.[17]

Of the three states studied, two use the county as the basic local unit for community programs and one uses multicounty regions.

D. WHERE DOES ILLINOIS STAND?

Since 1960 the delivery of mental health services in Illinois has followed the national trend of transitioning from institutional-based to community-based treatment and care. From 1960 to 1973, Illinois mental institution resident population declined 66 percent, while outpatient cases in both state-operated and state-aided clinics increased 900 percent! In 1973, patient care episodes in state mental institutions accounted for only 44 percent of all episodes, with most of the remaining 56 percent treated in outpatient services.[18]

MENTAL HEALTH POPULATIONS AND FINANCES IN ILLINOIS, THE U.S. AND OTHER STATES

CHART I-3

	U.S. Total 1969	Illinois FY 1973	California FY 1970	New York FY 1970	Kentucky FY 1970
Population Statistics					
Total population	201,300,000	11,250,000	20,000,000	18,250,000	3,200,000
Patient Care episodes[a]	3,464,000	[b] 290,000	[b] 328,000	[b] 540,000	[b/c] 31,000
Rate per 100,000 population	1,721	2,578	1,640	2,958	1,000
State/county mental hospital inpatient episodes	767,100	46,200	57,400	118,300	12,200
Rate per 100,000 population	384	411	287	648	381
Community out-patient episodes	N/A	150,400	197,100	400,300	17,000
Rate per 100,000 population	–	1,337	986	2,193	531
State/county mental hospital residency, end of year	[d] 338,000	15,200	12,700	64,400	4,700
Rate per 100,000 population	166	135	63	354	146
Median length of stay for direct discharge	N/A	30-59 days	14-21 days	57 days	[f] 123 days
Financial Statistics					
Source of Funds in Support of MH Programs[e]	$3,761,000,000	$390,000,000	$213,000,000	$735,000,000	$28,900,000
State Government[e]	1,617,000,000	304,000,000	143,000,000	500,000,000	20,500,000
Federal Government[e/g]	821,000,000	29,000,000	27,000,000	88,000,000	6,500,000
Local Government[e]	(included in State)	7,000,000	13,000,000	43,000,000	200,000
Private Sources[e]	1,323,000,000	[h] 27,000,000	16,000,000	59,000,000	1,600,000
Undifferentiated/Other[e]	–	[h] 23,000,000	14,000,000	45,000,000	100,000
Total Funds per capita	$18.68	$34.67	$10.65	$40.27	$9.03
State Funds per capita	N/A	$27.02	$ 7.15	$27.40	$6.41

[a] *All inpatient and outpatient services excluding VA hospitals*
[b] *State-supported services only*
[c] *Incomplete*
[d] *1970*
[e] *Rounded to nearest $100,000*
[f] *Mean*
[g] *Does not include public aid reimbursements*
[h] *Estimate only. Based on California and New York amounts as percentage of total expenditures.*

Sources: National Institute of Mental Health, Financing Mental Health Care in the United States, D HEW Publication No. (HSM) 73-9117 (Washington, D.C., 1973): State of Illinois, Mental Health Statistics for FY 1973; State of Illinois, Review of FY 1973 Budget Request, Department of Mental Health; National Institute of Mental Health, Age, Sex and Diagnostic Composition of Resident Patients in State and County Mental Hospitals, U.S. 1961-1970, Statistical Nov. 1972, Dec. 1972.

Viewed nationally, the Illinois record is substantially consistent with other state experiences. Chart I-3 compares Illinois with the national picture and the records of California, New York, and Kentucky.[19]

PATIENTS

The Illinois rate of total patient care episodes per 100,000 population is higher than the national average and the rates in two of the other three states. National figures, moreover, include patients treated privately with no public support, while the state figures do not. Illinois inpatient episodes in state mental hospitals exceed the national rate by 7 percent and are higher than two of the other three states. New York's rate is substantially higher (89 percent above the national average). In terms of state mental hospital residency at the end of the reporting years, Illinois rate per 100,000 population is lower than the national average and that of two of the other three states.

COMMUNITY SERVICES

Illinois community-based system seems less well developed than the systems in some other states. The Illinois rate of community facility outpatient episodes per 100,000 population is higher than the rates in Kentucky and California, although lower than in New York.

While Illinois record in community-based services compares well, the state is constrained because of the nature of the state/local institutional and financial arrangements to provide treatment and care. California, New York, and Kentucky all define one, and only one, political jurisdiction responsible for delivering local services. California and New York use the county; Kentucky uses multicounty regions. In each case, these units of government *must* provide mental health services. In Illinois, counties, municipalities, townships, or any combination *may* elect to provide the local services under the prior named three separate pieces of legislation, but they are not required to do so. Charts I-4 and I-5 illustrate the extent to which local units of government have opted to provide mental health services. There are gaps, and the result is that many Illinois residents must continue to rely on the state as their primary treatment source.

STATE/LOCAL RELATIONSHIPS

California, New York, and Kentucky have formulas for sharing expenditures in the delivery of services: California provides for 90-percent state and 10- percent state and 10-percent local; New York and Kentucky legislate a fifty-fifty split. Illinois has no such legislative or administrative formula. Community programs are funded by the state on the basis of need only. In FY 1973 the ratio of state to local funding for community-based programs was approximately eighty-twenty. Despite the lack of a specific formula, *Illinois now provides proportionately more support to local programs than two of the three states surveyed.*[20]

MONEY

Financially, although figures are incomplete, total expenditures per capita (i.e., related to total population) for mental health in Illinois appear to exceed the national average and the per-capita expenditures of two of the other three states (see Chart I-3). The proportionate and per-capita state share is greater in Illinois than in two of the other three states. *Moreover, in Illinois 86 percent of the state expenditure is for the operation and maintenance of the state hospital system. (Comparable figures were not available for the other states.)*

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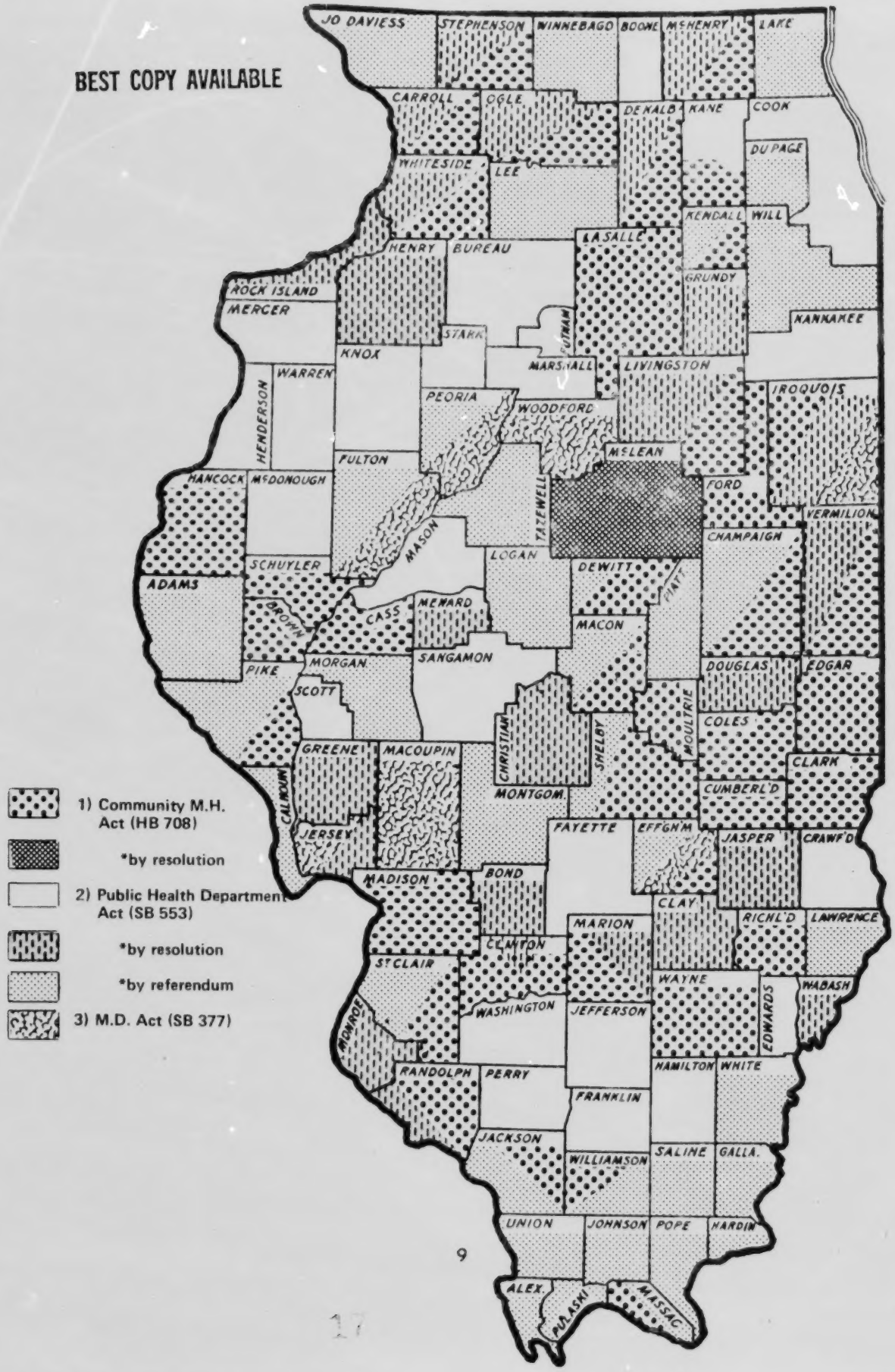

STATE OF ILLINOIS - DEPARTMENT OF MENTAL HEALTH

PLANNING AREAS - REGION 2

January 1972

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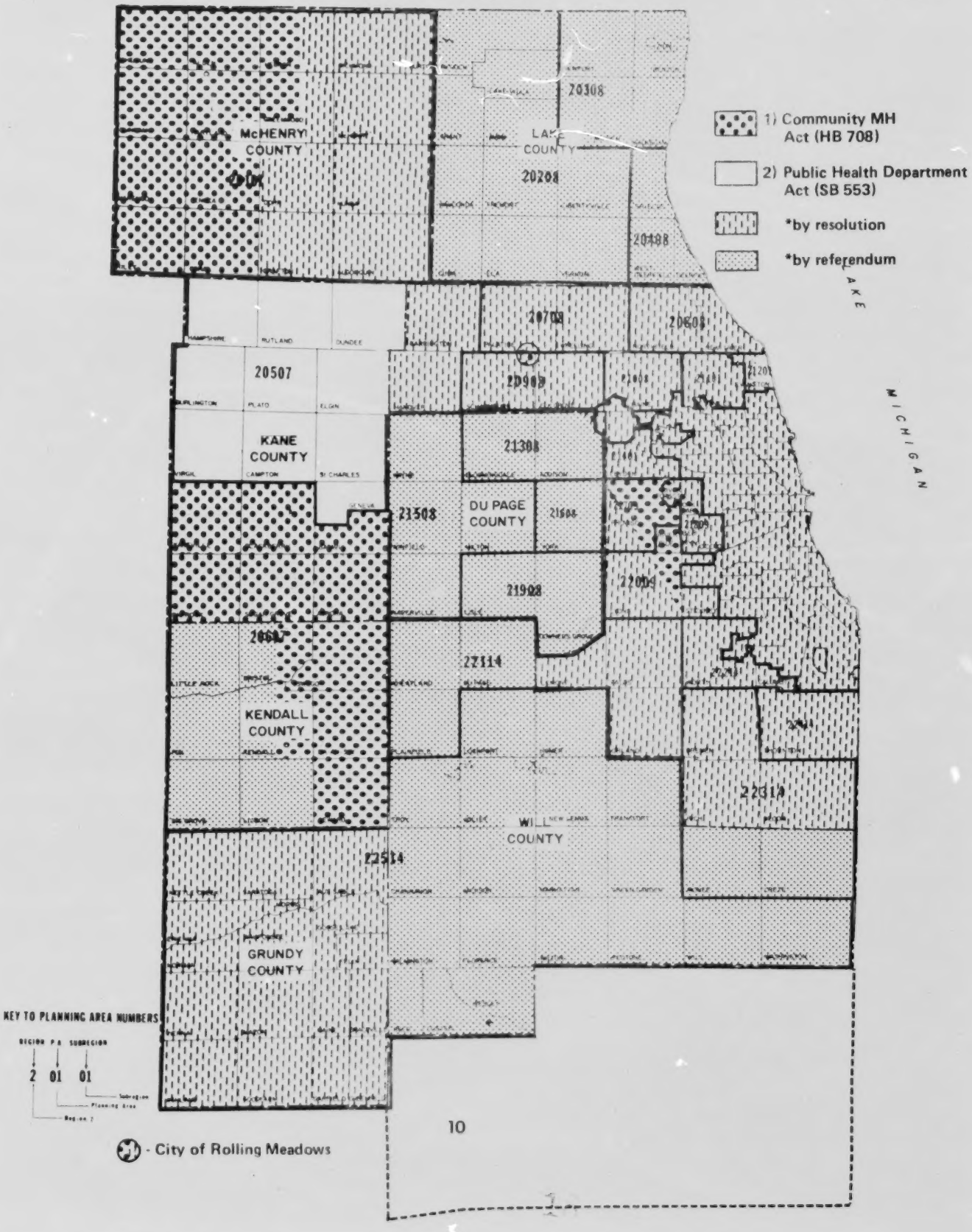

The major conclusion from this comparative analysis is that while Illinois has followed the national trend, it is – and always has been – handicapped in moving from institution-based to community-based care when warranted. Illinois has – and will always have – an institutional system to treat and care for those persons who are not yet able to return to their communities. But, Illinois has no consistent, single system for providing care and treatment in the community for those persons who can most benefit from it. Other states do. Illinois permits local governments to fund services. Other states require it. Illinois has a substantial amount of its state mental health budget tied to institutional care. At least some other states have been able to reduce their state institutional costs more substantially.

Comparative analysis is useful to the extent that it puts issues and conditions into perspective. However, comparative analysis side-steps the central questions: Do Illinois residents have available to them the best possible mental health treatment and care? If not, what is being done (and what can be done) to deliver such treatment and care? These questions will be the topics of Chapters Two, Three, Four, and Five.

CHAPTER TWO: THE DIRECTION OF MENTAL HEALTH AND DEVELOPMENTAL DISABILITIES IN ILLINOIS

The Illinois Department of Mental Health and Developmental Disabilities (name changed by legislation in 1974) has a specific goal and overall implementing policies for the effective care and treatment of Illinois residents. Many governmental units, organizations, and individuals are affected by – and influence – this goal and Department policies. All participants have criticized and identified problems involving their pursuit. These matters are the subjects of this chapter.

A. GOAL AND POLICIES

1. *The Goal*

THE DEPARTMENT OF MENTAL HEALTH AND DEVELOPMENTAL DISABILITIES SEEKS TO ACHIEVE, IN EACH ILLINOIS COMMUNITY, A COMPREHENSIVE DELIVERY SYSTEM OF LINKED MENTAL HEALTH AND DEVELOPMENTAL DISABILITIES SERVICES PROVIDING EFFECTIVE TREATMENT AND CARE FOR ALL PERSONS IN NEED OF SUCH SERVICES.[1]

a. *Goal Interpretation*

Several key phrases in the goal statement require definition.

Community: for the purpose of delivering mental health and developmental disabilities services, a *community* is a federally approved mental health *planning* area, which may include populations ranging from 75,000 to 200,000 people. There are eighty-three planning areas in Illinois (see Charts II-1 and II-2). Inasmuch as counties, multicounties, townships, and municipalities may now deliver their own independent services, it has been difficult to develop systems of linked services in the planning areas. Department officials believe that before comprehensive delivery systems can be implemented effectively in each community, two changes must occur: a *community* should be defined in terms of smaller population sizes (i.e., 25,000 to 75,000), and the largely independent services delivered by agencies within these communities must be linked if they are to receive Department financial support.

Comprehensive delivery system of linked services: in each community, the goal is to connect all program services, from client referral to discharge. Thus, from whomever the client initially sought help, he would be in the delivery system of that community and assured of assistance and guidance in obtaining needed services from all appropriate agencies in that community. The system must be *comprehensive,* including all program services necessary to meet the specific needs of the community's population.

Mental health and developmental disability: there is an accepted professional definition of *developmental disability.* We can determine who is developmentally disabled and therefore in need of treatment and care. There is no accepted professional definition of *mental health* or *mental illness.* Even psychiatrists disagree on definition. The Department's position is that, if there is to be a definition of mental health and mental illness, it must be expressed by each Illinois community.

Effective treatment and care: services must be delivered to restore patients to a functional level and adequate social competence in their communities. This interpretation differs slightly from Department policy articulated in 1969, which placed emphasis on the development and promotion of effective programs for both the *treatment* and *prevention* of mental disorder.[2] Interestingly, although Illinois mental health legislation addresses treatment and care, *prevention* – as a specifically authorized Department program service – is mentioned only with respect to alcoholism. While recognizing the importance of programs to prevent mental illness and mental retardation, the Department today, with its limited resources, wants to ensure that treatment and care is effective for persons most in need before addressing, in a major way, the *prevention* of mental disorder. Department professionals are, however, deeply concerned about the complex issue of primary prevention.

All persons: the Department's responsibility is to ensure the availability and adequacy of services to all residents of the state, regardless of their particular life circumstances. The Department has long recognized, however, that it must *"....emphasize services.....programs aimed at the lower income groups. This does not imply discrimination against the middle class; rather, it recognizes that lower (economic) class patients, because of financial inability or lack of understanding methods of gaining access to community resources, are frequently the least well-served."*[3]

b. *Goal Assumptions*

In pursuit of this overall Department goal and in developing the policies to achieve it, the Department has made certain assumptions concerning the treatment and care of persons in Illinois.

First, treatment and care of most patients is optimally effective in the community.

Second, for some patients long-term institutional care is the only solution, and state institutions, under foreseeable circumstances, will always be required for their care. Privately owned and operated institutions could conceivably be developed to replace state institutions, but there is no definitive indication that they will be developed to do so. In Illinois it is estimated that state facilities will always be needed for a substantial number of mentally ill and developmentally disabled persons who require long-term/residential care.[4]

Third, given competing demands for state financial resources, the Department cannot afford to fund program duplication. Legitimate demands by Illinois citizens for money for other human services and other programs could not be satisfied if the Department of Mental Health and Developmental Disabilities funded duplicate program services for the same populations.

Fourth, the State of Illinois is responsible for the major share of public expenditures for the treatment and care of its mentally ill and developmentally disabled residents. The Department cannot transfer this financial responsibility to other levels of government.

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KEY TO PLANNING AREA NUMBERS

STATE OF ILLINOIS - DEPARTMENT OF MENTAL HEALTH

PLANNING AREAS - REGION 2

January 1972

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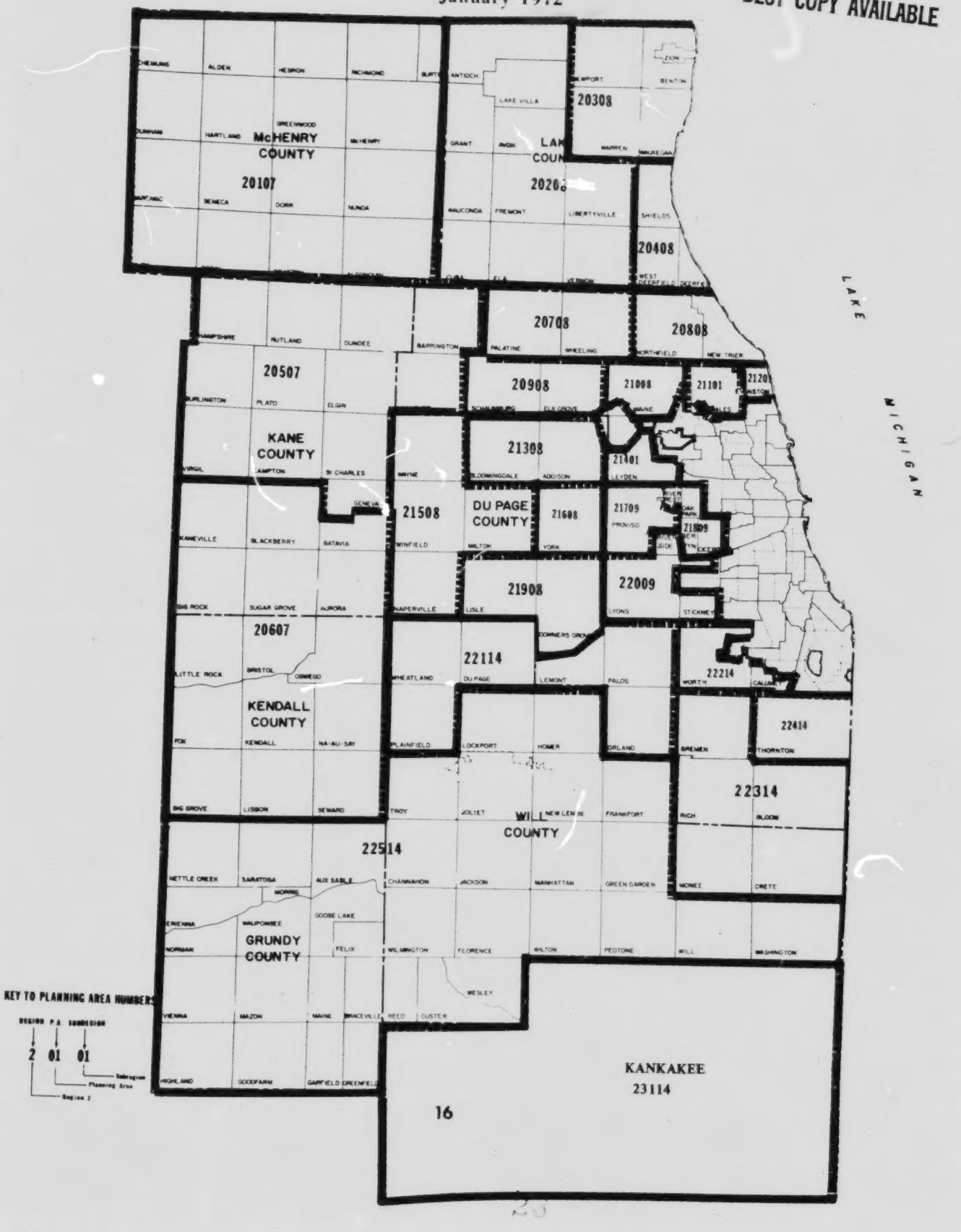

2. *The Policies*

Given the goal, its interpretation, and the above four assumptions, the Department has the following policies:[5]

In funding community programs, the Department's first financial responsibility is to guarantee the major costs for treatment and care of all former Department patients and those persons in danger of being extruded from the community because of mental illness or disability.

The Department shall deliver or fund a full range of different treatment, care, and rehabilitation program services for different kinds of disabilities (i.e., mental illness, developmental disability, alcoholism, drug abuse). All patients shall have access to any of the services – regardless of the particular diagnostic label (e.g., mentally ill, mentally retarded) – he may have received because of an immediate programmatic need.

State institutions will be integral parts of comprehensive delivery systems in each community.

Communities shall be responsible for planning their comprehensive delivery systems, in coordination with the Department.

Community-based programs that are alternatives to state-operated programs must be at least as adequate or better than the state programs they replace.

In operating its own institutional programs, the Department must provide the most effective treatment and care possible.

In transferring clients from state institutions to long-term care facilities in the community, the Department must ensure that the care and treatment in those facilities is the most appropriate and effective available for the clients served.

B. ANALYSIS OF THE GOAL AND POLICIES

The majority of mental health and developmental disability participants in Illinois have long supported, at least in principle, the Department goal of achieving, in each Illinois community, a comprehensive delivery system of linked mental health and developmental disability services providing effective treatment and care for all persons in need of such services. They agree that long-term institutionalization is harmful to most patients, and that their effective treatment and care in the community is the only realistic alternative.

However, these participants – principally members of the State Legislature, provider organizations, local governments, and citizens associations – have severly criticized the Department's actions to achieve this goal. Specifically, they have objected to the Department's goal interpretation, some of the assumptions upon which the goal is based, and many of the policies that apparently guide the goal's pursuit.

Some of the criticisms are valid, pointing out problems the Department must resolve. Other criticisms result from philosophical differences; while they may be opposite views, their full airing may help the disputants better understand each other's positions. Many criticisms come from participant misunderstanding of what the Department is trying to accomplish – and actually doing.

The purpose of this section is to examine the major criticisms of the Department's pursuit of its goal and policies. The hope and expectation is that this examination will enable all participants (including the Department) to join together in improving the delivery of mental health and developmental disability services to the residents of Illinois.

1. *Criticism of the Goal*

THE ROLE OF PLANNING

One of the most universal criticisms is that the Department of Mental Health and Developmental Disabilities does no planning. It may know where it is going, but it has no detailed map for getting there. Many people believe the Department must develop and make public step-by-step plans for the full transition to comprehensive delivery systems of linked services in each community. Moreover, they believe that citizens should participate in the development of those plans.

For several years the Department has not given sufficient attention to long-range planning leading to achievement of its goal. In a public agency with 20,000 employees and annual budgets exceeding $350 million, it is surprising that there is neither an office of planning nor a group of people charged with developing, coordinating, and updating long- and short-range plans. The situation, however, is understandable. When at least 90 percent of the budget is tied to operating and maintaining state institutions and most of the costs are fixed, planning occasionally seems to be a marginal endeavor. Additionally, the purpose of long-range planning is frequently misunderstood by the public. Once a plan is published, it is judged unalterable (which it decidedly is not). Public interests opposed to certain plan elements begin to lobby immediately against its implementation rather than examine the reasons behind certain critical decisions. Changes or potential reductions of programs in state facilities are some examples.

In many public agencies, planning's importance is criticized because results have not seemed germane to program operations. Planning has been done independent of programs. In Illinois the existence of the Mental Helath Planning Board helps downplay the Department's planning role. The Board, independently created by the State Legislature, is charged with developing

> *".....a continuous, long range planning program which will provide fullest utilization of existing resources, and to determine, in order of priority, additional services and facilities needed to provide a comprehensive, statewide mental health and mental retardation program that will meet the needs of Illinois."*[6]

The Mental Health Planning Board is the state agency charged with developing the mental health component of the comprehensive state health plan. Small wonder that the Department has not considered long-range planning one of its priorities.

The situation is changing, however. The Department has initiated long-range plan development for both mental health and developmental disabilities. Initial drafts are being prepared, and the Department will circulate them to a wide variety of citizen organizations for comment and contribution. The final plans must be sufficiently detailed to indicate where the Department is going, why, when it plans to get there, how it proposes to do so, and how much it might cost. The plans must also be revised annually to reflect new conditions, such as national health insurance plans, Federal standards review organizations, Federal community mental health center legislation, etc.

Citizen participation in this planning process is difficult and complicated to address. Adoption of mental health and developmental disabilities plans for the state, as they relate to clients served by the Department, must be done by the Department. The Department alone is ultimately responsible for their clients' effective treatment and care. The citizens' role can only be *advisory* unless a citizen is appointed to a statutory commission or committee. Moreover, the types of issues that nonprofessional citizen groups are competent to address is blurred. The Department's concern is that everything be done *"in the best interests of the patient."* In an agency managed by mental health and developmental disability professionals, the tendency is to address most issues in terms of patient interests, as defined clinically.

Actually, many of the major planning decisions concern public policy as well as or rather than clinical diagnosis. For example, the decision to transfer patients from state institutions to the community must be made clinically; the *rate* of transfer of groups of patients is both a clinical and a public policy decision. The quality of treatment and care is a clinical issue. No lay citizen can successfully challenge a professional's judgment as to which type of treatment is best for an individual patient. If citizens are to have an effective voice in the Department's planning, both the Department and the appropriate citizen groups must agree beforehand on the types of planning issues that each is most competent to address.

The recent creation of a citizens' advisory council for community mental health services will help. The statewide fourteen-person council will review and evaluate funding mechanisms for new community mental health services and will make recommendations to the Department on grant-in-aid applications from community agencies. Later this year, seven regional councils will be established to review grant-in-aid applications and advise on policies and programs in their regions.

But this is just a beginning in a specific area. The Department will establish on-going mechanisms for involving citizen groups at critical stages throughout the planning process.

COMMUNITY MENTAL HEALTH

There is little agreement on what constitutes community mental health – not surprising since there is little agreement among professionals on a definition of mental health itself. The lack of agreement on a definition of community mental health is more than semantical. The Department, which is the major source of funds for most community mental health agencies, can fund only certain program services for certain classes of patients. The community may wish to offer mental health services to other classes of patients, and it may even want to conduct programs to prevent mental illness. For the community, all these things can be community mental health.

The Department states that any community may define community mental health as broadly or as narrowly as it wishes. Community mental health programs currently eligible for Department *funding*, however, are defined as *those services which are necessary to restore to functional level and adequate social competence all those persons who are former Department patients or who are in danger of*

being extruded from the community because of mental illness or disability. The Department will guarantee major funding for these necessary services. The community must find alternative funding sources for all other desired program services.

There are several reasons for the Department's definition. *First*, it is a matter of priorities. Given limited state resources and the accepted conclusion that community-based treatment is better for most patients, the Department must first ensure that those patients most in need are receiving effective treatment and care.

Second, Department executives believe that mental health professionals are not the only group to develop, implement, and sustain effective programs to prevent mental illness and disability. This is a strong statement coming from executives who are mental health professionals. Most people agree that many social problems – discrimination, poverty, poor education, bad living conditions, impaired quality of life, etc. – do contribute to mental illness. If they were solved, mental illness incidence would probably decline. The disagreements emerge over who should address these social problems – and how. Department executives argue that the professionals trained to treat mental disorders are not trained to administer to many of the underlying societal conditions that may have contributed to them. Even if mental health professionals were so trained, it is doubtful that communities would permit them to play dominant roles in trying to improve social conditions. Psychiatrists are associated with trying to change and modify individual behavior. If they were also viewed as trying to change and modify societal behavior, they might be seen as manipulative and Orwellian – to the detriment of the mental health profession and its primary mission.[7] We must also recognize that no political body in any community, state, or nation has ever declared public policy to be the treatment of society's problems as problems of mental health.

Mental health professionals do not remain aloof from detrimental social conditions. They do work toward and support changes to ameliorate these conditions, *as concerned and capable members of their communities.*

Debate on the merits of preventive psychiatry will continue. It is discussed in this paper not to resolve the debate, but rather to present the Department's reasoning for not funding *"preventive psychiatry"* programs.

The Department's definition of community mental health has confused and angered many community service providers because they contend that the Department has changed the rules of the game. Previously, they say, the Department placed no restriction on the types of patients to be served in the community. To do so now threatens many of the program services which the Department previously encouraged and supported. Operationally, their argument is undoubtedly true. However, Department policy for twenty years has been to give priority consideration to patients in greatest need. Mental Health Regulation 74, implemented in 1953, required any facility receiving state grants to treat those former state mental hospital patients and all conditionally discharged patients who were referred to them. In its haste to support new community facilities, the Department may have been remiss in reinforcing this regulation. Restricting state grants-in-aid to programs for patients most in need may threaten some excellent community services. The only solutions would appear to be to remove the restriction and substantially increase the budget of the Department, to care for these patients in state mental institutions where they do not belong, or to find alternative sources of funding.

Another criticism of the Department's definition of community mental health is that it conflicts with the definition by the National Institute for Mental Health which provides construction and staffing grants for comprehensive community mental health centers. They offer a variety of mental health services to everyone in their service area, with no priority given to persons in greatest need. Even preventive psychiatry, under the category of consultation and education, is an essential program service. It is argued that inasmuch as the state approved each community grant application and has provided grants-in-aid to these centers, it has supported the services they are offering. Changing the conditions of state grants jeopardizes these centers.

The argument is justified, but it places the Department in a difficult position. The original goal of the federal program authorizing these centers was represented to Congress as the construction and staffing of facilities to replace the state hospital – to move the care of the mentally ill from the large state institutions into the community.[8] Sight of this original goal was lost. One evaluator found *".....considerable tendency to exclude from inpatient care any person believed to require more than brief treatment ....."*[9] He goes on: *"The evidence is abundant that many of these persons (chronically ill and chronically impaired) could live at least partially satisfying and productive lives if the support they need was available to them.....Such facilities are prescribed in the Federal regulations as part of a COMPREHENSIVE mental health center program – but they are optional, not ESSENTIAL."*

Many Federally funded community mental health centers are excluding patients most in need. *The problem is compounded: the Federal share of staffing these centers declines over a seven-year period to zero, and the centers then expect the state to fund the large portion of that Federal share.*

The Department admits that its priorities may differ from the evolved priorities (if not the original goal) of the Federal Government and the community centers they helped create. However, if the patients in greatest need are to be provided mental health services in their communities, the Department must ensure that those services are available; funding is the only leverage it has.

STATE FUNDS FOR COMMUNITY MENTAL HEALTH

Debate goes on as to whether the state is committing sufficient financial resources to develop comprehensive delivery systems in each community. Proponents of sizable increases in state grants-in-aid argue that the sizable increase in grants over the 1963-1973 period is irrelevant to their position: ten years ago grants were small, and the need now is far greater.

The Department agrees. Fully developed comprehensive service delivery systems would undoubtedly require increased funding. But the Department also acknowledges that while mental health may be a state priority, it is not the *only* priority. Sizable funds are also needed for the other human services. The Department has therefore taken the position that while increases in the grant-in-aid program can be expected every year, the annual increases have limitations. As experience with the Federally funded community mental health centers has demonstrated, communities cannot always use effectively sharp increases in funds.

The Department has experimented with a formula for determining which portion of its budget in any year can be allocated to the grant-in-aid program:

- The Department starts with the budget allocation for mental health which has been developed in conjunction with the Bureau of the Budget. This allocation is based on previous expenditures for mental health, projected available resources to the state, and mental health's priority in relation to other state funding requirements.

- The budget allocation is divided by the total state population, resulting in a per-capita budget allocation.

- The per-capita budget allocation is then multipled by the population in each of the eighty-three planning areas, resulting in eighty-three budget allocations.

- From the budget allocation for each planning area, projected state expenditures for state-operated inpatient and outpatient care, interim care, and purchase of care are subtracted. These state expenditures are tied to the patients from that planning area regardless of where the institutions are located which provide the care (for example, the planning areas in metropolitan Chicago, which has seven state facilities, are not charged with the total expenditures of those facilities). The result of this calculation is the *funds available to each planning area for community grants-in-aid, and in turn each region representing those planning areas.*

- From the grant funds available to each planning area, the previous year's grant funds are subtracted. *No planning area will receive less than it received the previous year.* If the result of this calculation is a surplus for each planning area, it gets the surplus (i.e., an increase in its grant-in-aid allocation). If, as is usually the case, some planning areas have surpluses and others have deficits (i.e., potentially less money this year for grants than last year), the surpluses are distributed to remove the deficits.*

Under the Department's formula, if communities do develop services for the patients in greatest need, they ultimately stand to obtain proportionately more grant funds per patient than they are now receiving because of the high operation and maintenance costs associated with large institutions.

2. *Criticism of the Policy to Offer Comprehensive and Coordinated Mental Health and Developmental Disability Services*

In 1973 developmental disability[11] services were almost removed from the Department into a new state agency. Instead, a Division of Developmental Disabilities was created in the Department, with a Deputy Director reporting to the Director of the Department.[12] The organizational change resulted from the alleged contention, supported by numerous citizen organizations and the majority of the State Legislature, that developmental disabilities were not being treated equitably in the Department. They argued that the psychiatrists, who *"control"*

*The Department recognizes that metropolitan areas and other communities with high incidents of mental illness may require, for the foreseeable future, a disportionate share of state funds.

the Department, are not sensitive to the specific problems of the mental retardation client; while a medical model of treatment may be necessary for the mentally ill, the model in mental retardation should be one of rehabilitation and education. Developmental disability has a quality of permanency which altogether does not exist in mental illness. The disability, although perhaps ameliorated, will always exist. Department priorities, they argued, were unfair to the developmental disabilities. Proportionately more money went for mental illness expenditures. If developmental disability were separated from mental health, they felt that more money would be available for needed care, rehabilitation, and education.

Department financial and client population statistics do not seem to support the notion that funds for treatment of the mentally ill receive priority over the developmentally disabled. At the end of Fy 1973, there were 15,200 residents in state facilities, *48 percent diagnosed as mentally retarded. Of the 149,000 non-resident admissions during the year to all other State-operated or State-aided facilities, 7 percent were mentally retarded. Combining these figures, 10 percent of those served were mentally retarded. Thirty-four percent of the Department's FY 1973 budget was allocated to treat and care for the mentally retarded.*[13]

Department officials know that treatment of a developmental disability has variabilities from treatment of mental illness. They know that treatment and care for the mentally retarded most often costs more than service to the mentally ill. They know that different professional skills are required for each type of treatment, regardless of the diagnostic category. They recognize that, in some institutions, mentally retarded patients have received lower priority. Changes have been and are being made. For example, education for the mentally retarded is now receiving much greater emphasis. The organizational elevation of developmental disability to equal status with mental illness was probably long overdue. However, the Department believes that complete separation of the two disorders is not in the clients' best interests. If they were separated, patients would not have readily available to them the full range of necessary treatment. A patient may be initially diagnosed as having both mental and developmental disability problems, although the primary diagnosis will label him as one or the other. If the programs were totally separate, the likelihood is that the person would always be labeled as either mentally ill or mentally retarded – with the frequent result that he would not have available to him all the services of the Department. While state institutions probably have some residents in mental illness units whose primary disability is mental retardation, it might be more difficult to discover this understandable overlapping if the two programs were completely independent.

Financially, a new department's creation always increases state expenditures – principally for administration. Assuming that over one- third of the Department's operations and grants budget is allocated to developmental disabilities, and applying the rule (supported by the FY 1973 budget request) that approximately 5 percent goes for administration (some of which would have to be duplicated), the creation of a new department would increase state expenditures by approximately $5 to $8 million per year. Use of these funds for community programs is obviously of more benefit.

3. *Criticism of the Policy to Guarantee the Major Costs of Treatment in the Community for the Persons Most in Need*

Critics argue that this policy (a) discriminates against many people who need mental health and mental retardation services and is contrary to the state law of administering to all, (b) conflicts with previous state policies in funding community programs, and (c) is sufficiently ambiguous to result in inequities throughout the state.

The first two arguments were discussed above in relation to the Department's definition of community mental health. The Department's policy has a twenty-year history, although it is not always followed. The Department's policy does not *prohibit* funding of programs to serve citizens with lesser needs; it merely says that funds should be available *first* for those persons who are former state institution patients or who are in danger of being extruded from the community. Every public agency must establish priorities for spending its funds. Current resources available to the Department restrict funds to this priority group.

However, application of the policy has not always been consistent and has resulted in regional inequities. Former patients of state institutions can be identified. Those persons *"in danger of being extruded"* are harder to define. For the mentally ill, they are those who suffer from the major mental disorders (i.e., schizophrenia, manic depressive psychoses, major acting out disorders, suicidal depressions, sever organic brain disease). There have been instances, however, in which regional representatives have interpreted differently those *"in danger of being extruded."* One reason may be that they have not all been trained adequately in patient definition. Another reason is that communities throughout the state vary in their *tolerance* of mentally ill persons. Some communities would extrude persons that other communities would not. Each community dictates the level of accepted deviancy.

For the developmentally disabled, they are the persons whose disability is attributable to mental retardation, cerebral palsy, or epilepsy which originates before the person reaches 18 years of age and which has continued or can be expected to be a substantial handicap to the individual.[14]

The Department and its regional and subregional representatives for both mental illness and developmental disabilities are responsible for spending considerable time with community agencies, helping them understand fully how to identify those patients who are in danger of being extruded.

4. *Questioning of the Policy That State Institutions Will Be Integral Parts of Community Delivery Systems*

STATE HOSPITAL CLOSINGS

Many citizens believe that the Department will eventually close all state facilities. They see this as the ultimate result of the development of comprehensive delivery systems in every community. They don't believe the Department's statement that, under all foreseeable circumstances, *state institutions will always be needed for some patients.* These critics will view population reductions and every institutional closure as validating their belief. They will probably be convinced only by constant communication and education.

The Department has announced that it will close no institutions over the next year. Indeed, it is opening two new facilities and expanding and converting another. However, it is obvious that as community programs are initiated, expanded, and improved, the *need* for all twenty-seven facilities is lessened. Whether any will actually be closed is another question. The reasons are complex and volatile.

First, there is the community fear that if persons with major mental disorders are treated outside institutions, they potentially threaten the safety of all the residents. This fear is encouraged by the media. Whenever a former mental health patient commits a crime, it is front-page news. There is *no evidence* that the mentally ill have higher crime rates than other citizens, but the fear persists.

Community education can only dimish but not erase this fear. Sociologists have consistently found that most of us are uncomfortable with people who act in what we consider abnormal ways. Moreover, while every community can absorb a certain number of "abnormal" persons, too many can seriously threaten community life. The experience in Edgewater-Uptown is a case in point. State institutions were initially established as much to protect the community from its abnormal citizens as they were to treat and care for patients. Both purposes continue to exist. David Mechanic, in his book *Mental Health and Social Policy*, states trenchantly that many studies have shown that a large proportion of patients in mental hospitals in the United States and other countries have no serious disturbances of behavior and are kept in the hospital for largely social reasons.[15] Decisions to place patients in institutions are based on a number of factors including religious beliefs, community cultural standards, family affluence, and the availability of long-term care facilities. In Illinois, there is some indication that the existence of a state facility in an area helps to create its own resident population. For example, Region 1A and 3B have no state-operated long-term care facilities. Their rates of institutional residents in relation to their populations are lower than in regions that have long-term care facilities.[16]

The Department's policy to develop community programs has been made largely for *clinical* reasons.[17] The community's willingness to accept patients most in need into these programs is a *public policy* decision, however, which must be determined politically – by frequent communication between the Department and the communities and, if necessary, by the courts.

Second, perceived threat to the community's security is not the only reason that many citizens oppose state hospital closings. Most state institutions have long been economic mainstays in their communities. They were intentionally located (isolated) away from major population centers in smaller communities. Their closing would result in substantial loss of income to the community. While their employees might find jobs, the community itself could probably not provide them.

Third, employees of state institutions and the unions that represent them also oppose closing state hospitals. They believe that closures mean loss of jobs or at least transfer of employees to less desirable ones. The problems of employee relocation are mammoth. Employees given the opportunity to transfer with programs to other state facilities face the uncertainty of living in a new community. Many may be qualified to work in community facilities, but the pay

may be less, continued employment less secure, and they lose some of their state benefits. Others may not have the skills or attitudes to work in community-based programs. In either case, many community agencies want to hire their own personnel. For some employees, unemployment – hopefully temporary – may be the only solution. The effort which the Department, through its Task Force on Employee Relocation, undertook to relocate the 671 employees at Peoria State Hospital illustrates the problem. Its efforts resulted in 35 percent finding other positions, 9 percent retiring, 22 percent resigning, and 33 percent laid off or discharged. Galesburg State Hospital had over 100 positions available to Peoria employees which were not taken.[18]

With no institutional closures now planned, the Department plans no major employee layoffs. Indeed, the opening of two new facilities will require additional personnel. If staff reductions are required because of further reductions in patient populations, they will be accomplished through normal employee attrition (not rehiring for a position when an employee resigns).

As has been painfully discovered in California and Massachusetts, the closure of state hospitals has become a public policy decision – to be determined in the broader political arena. The patients themselves sometimes become a secondary concern. Citizen fear of treating severe cases of mental illness in the community, legitimate concerns for a community's economic health, and labor's concerns for the preservation of employee jobs must be balanced against the clinical judgment that some institutions are no longer needed. However, if community and labor opposition were to prevail, some state institutions would eventually exist only to provide employment – and not to treat the mentally ill. Understanding this potential end-result, the citizens of Illinois would be extremely reluctant to tolerate any action by the Department to emphasize jobs (for jobs sake) over service delivery.

INTEGRATING STATE INSTITUTIONS

If the community delivery systems were fully developed, state-operated inpatient and outpatient services would be a limited program resource, to be used when no satisfactory program alternative is available and it would clearly be in the patient's and the community's best interests to treat and care for the patient in a state institution. In other words, the state facility will be a resource of last resort, as it now stands. Department executives feel strongly about this limited use. Research has shown that once a person has been in a state mental institution, he is always labeled as such, regardless of his subsequent condition.[19]

Currently, the state institution is not this resource of last resort. In most cases it duplicates treatment that should be provided in the community. Community clinics in an exploitative fashion tend to refer their most difficult patients to the nearest state facility. In his evaluation of Federal comprehensive community mental health centers, Glasscote observed:

> *"As long as it is possible to send off to some other facility any person presumed to need more than brief hospitalization, the staff are not likely to learn the extent to which some such patients can and do respond to brief treatment in an intensive program."*

It will take several years before the state hospital becomes a true part of community delivery systems, whatever the hospital's alternative use turns out to be.

5. *Concern About the Policy That Communities Should Be Responsible for Planning Their Delivery Systems*

There is no disagreement with the policy. However, so long as a community is defined as a *"planning area"* and there is no agency or board responsible for planning for services for the entire community, the planning and coordination task must rest primarily with the Department.

6. *Concern About the Policy That Community-Based Programs Should Be at Least as Good as the State-Operated Programs They Are Replacing*

There is no disagreement with the policy. Some critics question whether the Department, in its *"haste"* to develop community alternatives, is following its own policy. There has been minimal program evaluation to justify the criticism. Critics do point to what they call the *"revolving door"* (i.e., the increasing readmission rate at state hospitals) as an indication that some community programs are not working. To them, the revolving door also indicates that many patients are discharged prematurely from state institutions.

Readmissions have been increasing since 1960, although in the last few years the increase has been less than 4 percent per year. In fact, the annual increases in readmissions have declined as community grants-in-aid have increased.[21] The readmission rate (the percentage of people requiring readmission) of 60 percent may seem high. Such a rate is not basically an indication of poor treatment. Many patients can be expected to enter institutions several times over the course of their treatment. If they remain in an institution too long at any one time, the effect of *residence itself* may counter effective treatment. The time interval a patient spends in the community between admissions is clearly a more effective measure. In its evaluation of funded community programs, however, the Department watches closely in each planning area the number of first admissions, readmissions, and the number of persons residing in state institutions as indications of community program effectiveness.[22] Substantial increases would require examination.

The Department knows that monitoring community program effectiveness can be improved. In some Department regions, subregional directors (or their deputies) visit their community agencies regularly to observe and talk over problems. They know firsthand how effectively the services are being provided. In other regions, the Department/community contact is much less frequent, with the possible result that programs in those regions may suffer.

The problem with evaluating relative program effectiveness is that there has been little evaluation of any program, state- or community- operated. Nationally, Glasscote observed:

> *"While it is known.....from a few isolated investigations that a percentage of persons generally treated as inpatients can be treated as day patients or outpatients, it is not known WHAT percentage, because there have not been comprehensive saturation experiments in the delivery of service to designated target populations."*[23]

More importantly, it is not certain that all mental health participants (e.g., staff, program sponsors, citizen groups, management, patients, researchers) could agree

on the criteria to evaluate and compare programs. Krause and Howard point out:

> *"Not only does each party to a service program have its own (implicit) evaluative criteria and standards of evidence for judging the program, but in addition the parties may have the same or different functional roles relative to the research than they have relative to the action program."*[24]

7. *Concern About the Policy That, in Operating its Own Programs, the Department Must Provide the Most Effective Treatment and Care*

PATIENT CARE

There is obviously total agreement with the policy. Some critics question, however, just how effective the Department is – particularly with respect to *care*. *First*, they point to incidents among patients or between patients and staff as an indication that the Department has reduced the staff assigned to care directly for the patients below a level that will ensure the most effective care.

The Department has actually increased the ratio of staff to patients since 1970. Chart II-3 presents a series of staff/patient relationships from 1970 through 1973. The average daily inpatient population declined 36 percent over this period, while the number of Department employees decreased only 7 percent. The ratio of total staff to patients exceeds one employee per patient.

Obviously this is not a fair comparison. Forty-one percent of the staff does not provide direct treatment and care, and an estimated 8 percent of patient care employees are primarily assigned to outpatient rather than inpatient services. Eliminating this 49 percent, there are approximately seven inpatient care employees for every ten patients. This ratio has increased by almost half since 1970, with the major part of the increase assigned to the *care* and *protection* of patients. Today, there are almost one and one-half *treatment* personnel (psychiatrists, psychologists, social workers, physicians, physical therapists, etc.) for every ten patients (as opposed to slightly more than one staff per ten patients in 1970). There are more than five *care* and *protection* personnel for every ten patients (contrasted with less than three and one-half in 1970). Even that ratio, however, is slightly misleading. Approximately five and one-third employees are needed for every one care and protection staff member because of vacations, absences, and the need for twenty-four-hour, seven-day coverage. On the average, at any given time there is one care and protection employee for every ten patients, almost a doubling since 1970 when slightly more than one staff member had to care for twenty patients. The ratio is, of course, higher during the day and lower at night when patients are in bed.

The facts clearly demonstrate that the quantity of direct inpatient care staff has significantly increased in relation to the number of patients. The facts say nothing about the quality of care or the institutional distribution of staff. The Department depends on labor market availability and how competent the staff members are. Assuming that conditions have not changed markedly since 1970, it is concluded that patients are better attended today than they were four years earlier. Whether the number of staff should increase even further is another question.

It is important to understand that the public (particularly citizen organizations and their legislative representatives) and the Department approach unavoidable,

STAFF/INPATIENT RELATIONSHIPS
FY 1970-1973

Chart II-3

	FY 1973	FY 1972	FY 1971	FY 1970
Average daily inpatient population	17,393	20,293	23,590	27,055
Number of Department staff	21,446	22,755	23,733	23,036
Ratio: total staff/inpatients	1.23	1.12	1.01	.85
Number of Department patient service staff assigned to inpatients (est. 92%)	11,707	12,019	12,674	12,136
Ratio: inpatient staff/inpatients	.67	.59	.54	.45
Number of Department inpatient staff assigned to treatment	2,427	2,425	3,055	2,940
Ratio: treatment staff/inpatients	.14	.12	.13	.11
Number of Department inpatient staff assigned to care	9,280	9,594	9,619	9,195
Ratio: care staff/inpatients	.53	.47	.41	.34
Number of Department care staff on duty, on the average, at any point in time	1,740	1,799	1,804	1,724
Ratio: on-duty care staff/inpatients	.10	.09	.08	.06

Source: Division of Information Services, Illinois Department of Mental Health and Developmental Disabilities.

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unfortunate institutional incidents from a different perspective. The public tends to generalize from each incident that there must be hundreds more that go unreported and are therefore indicative of patterns. The Department, on the other hand, realistically treats each incident independently until a point when the accumulation of such incidents suggests a pattern requiring an institutional change. With 20,000 employees and 15,000 resident patients, it cannot do otherwise. If institutional changes were made following every incident, staff would be constantly apprehensive as to its roles and responsibilities. Citizen groups could better help ensure effective patient care if they were to work dispassionately with the Department in examining the rate of untoward incidents in each institution as an indication of more deep-seated problems.

With 15,000 resident patients, there is no doubt that there will be incidents of questionable patient treatment. Occasionally and unintentionally patients' rights will be abridged. No one officially represents the patients when these incidents occur. Technically, of course, the Department does – but it is a party to the action. Several organizations and individuals have therefore proposed the establishment of an independent ombudsman to represent the patient in trying to resolve conflicts.[25] Essentially, the ombudsman would have the power of persuasion: he could investigate, advise, criticize, and make recommendations, but he could not reverse administrative decisions.

The ombudsman concept is attractive, but it must be carefully developed. Should the ombudsman's mandate be restricted to the patient's *care* and *rights*, or should it extend as well to the patient's therapeutic *treatment*? Different *psychiatrists* may disagree on what is the most effective treatment for a given patient; the ombudsman would have no firm basis on which to investigate and challenge a patient's treatment plan. The point is that if an ombudsman system is to be implemented in Illinois, the system designers must first agree on the specifics of the ombudsman's role: what he can legitimately investigate and what he cannot.

Second, critics are justifiably upset with the poor physical conditions of several state institutions. As the Director has pointed out, these conditions result from Department neglect over a number of years, and sufficient funds are not available (nor should they be) to correct all the deficiences at once.[26] However, the Department's FY 1975 budget includes $34.8 million for physical improvements to 22 institutions (54 percent for developmental disability facilities, 46 percent for mental illness institutions). Funds will be spent for new buildings, equipment, recreational facilities, resident renovations, air conditioning, support system rehabilitation, and other important institutional improvements.[27]

Third issues of proper and fair care and treatment occasionally emerge which have institutionwide implications and which should have been addressed long ago. One such issue is so-called *"patient peonage"* – the longstanding practice of using patients as supplemental maintenance staff at little or no compensation. The justification for the practice was that the work was a part of patient therapy and treatment. The public has questioned the practice and its justification, and in November 1973 the United States District Court for the District of Columbia ruled that the minimum wage and overtime compensation provisions of the Federal Fair Labor Standards Act apply to institutional patients. *The Department has moved to implement the court's ruling, halting the work for over 90 percent of the patients (approximately 1,200) previously performing these maintenance*

functions. For the remainder (approximately 100 patients), work will be continued as part of their therapy program and compensated in accordance with Federal law.

Fourth, over the past year care of patients may have suffered because of staff anxiety that many employees may suddenly be laid off. People cannot function effectively if they see their security threatened. Moreover, many institutional employees professionally question whether some types of community treatment and care will be as effective as that which they are providing. While the layoffs have ceased, anxiety and anger remain. These difficult feelings must be addressed rationally.

PATIENT TREATMENT

In the eyes of the public, effective treatment in state institutions requires substantial numbers of qualified psychiatrist, psychologist, and other mental health professionals. Treatment, the public believes, primarily consists of individual and group psychotherapy. Thus, if our state institutions don't have enough of these mental health professionals, they should get them.

The State Legislature tried to force this issue in 1972 by requiring all the Department's limited-licensed physicians[28] to pass a professional test by July 1, 1974, or lose their licenses to practice in state facilities.[29] The practical effect of this action will be the discharge of the majority of these physicians, with little likelihood that the Department can find fully licensed replacements. Most experienced doctors and lawyers will say that if they were required to repeat their examinations after ten or fifteen years, they would fail.

The myth is that fully licensed psychiatrists, psychologists, and medical doctors can be found to work in state institutions. One issue is financial – they can earn more outside state-operated institutions. A second is numbers: there are not enough of these mental health professionals to work both in public institutions and in the private sector. Nationally, 90 percent of the public mental hospital manpower is nonprofessional aides. Psychiatrists and social workers account for less than 3 percent of the total.[30]

Mental hospitals care for the extreme cases of mental illness. Chu and Trotter observed that private psychiatric care is most often provided to the youthful, attractive, verbal, intelligent and successful.

> *".....psychiatrist rarely treat patients who suffer from brain dysfunction, severe psychosomatic disorder, metabolic deviance, perinatal trauma, and other disorders that require primarily medical attention. Neither do most psychiatrists treat individuals suffering from schizophrenia or manic-depressive psychosis. Such individuals make up the "hard core" of the mentally ill and the only mental health facility in which they appear in substantial numbers is the state mental hospital."*[31]

One might expect the Illinois State Psychiatric Institutes, which operate a mental health profession residency program, to produce a regular supply of professionals for state institutions. While many have indeed entered state service and others have participated in public psychiatry, graduates have many options open to them, and it is unrealistic to expect the majority to devote themselves to public service.

It would take a substantial reordering of mental health professional priorities across the nation for these trends to be reversed. Some critics argue that mental health should not be dominated by medical professionals. No one sees any reordering occurring. In many respects the State of Illinois is fortunate to have the services of its limited-license physicians. If it loses them, patient treatment in state institutions will have to change substantially.

8. *Concern About the Policy of Transferring Patients to Long-Term Care Facilities*

While few question the policy, its implementation has resulted in one of the strongest and longest criticisms of the Department. At its extreme, the criticism is that the Department is emptying its institutions of longtime elderly patients into totally inadequate nursing care facilities to the detriment of both the patient and the community.

In 1970 - 1971, state facilities discharged 2,900 elderly patients – 10 percent of total facility discharges. Twenty-six percent of the elderly discharged went to community placement. In 1971 - 1972, these facilities discharged 2,800 elderly – again 10 percent of total discharges. Fifty-three percent of the elderly went to community placement. In 1972 - 1973, 2,000 elderly patients (7 percent of the total)were discharged, an almost one-third reduction. Fifty-seven percent went to community placement. 1973 - 1974 discharges of the elderly will show even further reductions.

Why did the wholesale discharge occur in the first place? When the Department had 47,000 residential patients in the 1950's, by public health standards, state institutions were overcrowded 57 percent. Conditions were unbelievably bad. Many of these patients were elderly, placed in state facilities not because they were mentally ill but because they were elderly – and they had no place to go. The Department believed that almost any living situation would be preferable to the state institution. The Chicago Uptown area was perfect: once an upper-income residential area, the elite had moved to the suburbs, leaving large numbers of residential hotels. Building owners had the space; the Department had the need.

The Department admits that, given these conditions, it did literally *"dump"* patients into the community during those years. Superintendents were complimented by how rapidly they did it. Institutional employees welcomed it; they weren't going to lose their jobs because sufficient patients remained in the state facilities to require their care.

In 1969, the public began to expose the policy, and the Department began to address its very serious problem. Today, all community placements are in facilities licensed by the Illinois Department of Public Health, and the Department is required by law to visit the patient and the facility once a month for at least a year.

Patients are placed in three types of community care facilities: *skilled nursing facilities* (providing skilled nursing care, continuous skilled nursing observations,

restorative nursing, and frequent medical supervision); *intermediate care facilities* (providing basic nursing care and other restorative services under periodic medical supervision); and *sheltered care facilities* (providing personal care and assistance, supervision overnight, suitable activities, and medical care as necessary).[32]

In Illinois, there are 85,000 beds in licensed or provisionally licensed community care facilities; 66,000 are occupied, and 17,000 are former Department patients. Of the latter, 12,000 are receiving assistance through the Department of Public Aid.[33] Inasmuch as their financial assistance is shared equally by the Federal and state governments, this frees state funds for other mental health purposes. The Department of Public Health inspects the homes four times a year, and licenses are renewed annually. If the Department of Public Health finds that a home does not meet its standards and the deficiencies are not immediately corrected, it so advises the Department of Mental Health and Developmental Disabilities, which immediately transfers its patients to an acceptable facility. Critics say that while the system of licensing and monitoring may be adequate, the criteria for licensing is not stringent enough for mental health patients. More attention should be paid to the quality of the facility staff, programs, and activities. The Department admits that many facilities, particularly sheltered care, do not provide adequate programs.

However, this deficiency raises a broader public policy issue. Patients placed in sheltered care facilities have been clinically diagnosed as no longer acutely mentally ill, and, in accordance with the Illinois Mental Health Code, have been granted an absolute discharge. Clinically, they are indistinguishable from the non-former Department patients residing in the facility. For the most part, they are elderly persons who have no marked mental condition. They are quiet, could be receiving medication, and need to be cared for because they have physical problems. But they are the same type of patient placed in the facility by the community and the medical profession. The question is: Should former mental patients, with no current marked mental condition, receive a higher quality of care in these facilities than do the other residents? If facility care programs are inadequate, shouldn't concerned citizen organizations direct their attention to making the standards for *all* more stringent?

The Federal Government is doing just that. It is eliminating the sheltered care home as a facility qualifying for Federal assistance payments in caring for residents. All placements must be in skilled or intermediate care facilities. The Department will follow the Federal regulations in its placement. It will financially encourage a higher quality of care by providing a basic payment, then adding funds for needed physical health care and rehabilitation/activity programs. If sufficient community care facilities do not meet the Federal standards within the next year, the Department may be forced to return former mental health patients to state facilities – a grim prospect for those not mentally ill. More importantly, it is contrary to the State Mental Health Code.

It is likely that there will always be abuses of community placement and care. When identified, each abuse should be promptly corrected. But the citizen groups critical of Department community placement practices would better serve the mentally ill were they to focus their attention on those abuses and the system as it exists today rather than generalizing from the deplorable practices of the past – which have ceased.

C. THE ROLES OF MENTAL HEALTH PARTICIPANTS

Part of the public unrest concerning mental health in Illinois comes from the confusion and conflict over who does and who should do what in delivering services to the mentally ill and developmentally disabled. Chart II-4 categorizes the roles and participants, indicating what current role perceptions are.

Several observations demonstrate the conflicts. *First*, it is extremely difficult for any single body to be a policymaker, regulator, planner, monitor, funder, *and* advocate. The first five roles require an objective and somewhat detached posture to weight competing demands, conclusions, requests, and recommendations. The advocacy role, is subjective: it promotes one set of interests to the exclusion of others. Members of the State Legislature, however, have played the advocacy role as well as the five other roles which legislatures have traditionally assumed. One example of this role conflict is the legislative advocacy for converting one Chicago facility to long term care. Whatever the ultimate merits of this facility, legislators have assumed an advocacy position before the need has been assessed in terms of total Department needs. As the potential funder of such a facility, the legislators have, in effect, become both advocate and jury.

Second, the Department performs all eight roles. As a funder of community agencies, it must set policies and plan for, regulate, and monitor program conduct. In some cases, however, it has assumed an advocacy role (i.e., pressuring communities to initiate needed programs and the education system to assume primary responsibility for the education of mentally ill and developmentally disabled children). As an advocate, the Department appears to some people to be trying to pass off its responsibilities. As a provider of institutional services, the Department has also become one of the patient's protectors – sometimes difficult to do when it is the Department itself who is providing the service from which the patient needs protection.

Third, the only participant who has no role is the patient – for whom the whole system is built. Mental health patients are almost unique in human service delivery systems (perhaps along with children and incarcerated criminals) in that they have no say in their care and treatment. When ten other classes of participants try to speak on their behalf, there are bound to be conflicts.

Fourth, five classes of participants now have planning roles. When the delivery of mental health services was limited to state institutions, the Department (and perhaps the legislature) had the exclusive planning franchise. Planning has become far more complicated because of the legitimate interests and requirements of organizations at the state and local level. All must now be a part of mental health planning in the state.

Fifth, the proliferation of state advisory boards and councils has permitted a diffusion and a confusion of effort. Excluding the legislative commissions, there is the Illinois Mental Health Planning Board, the Board of Mental Health Commissioners, the Governor's Advisory Council on Developmental Disabilities, and the newly created citizens' advisory council for community services. To date, all of these groups have had little effect on the direction of mental health and developmental disabilities in Illinois. They do permit more citizens to "*advise*," but on what – or to whom – is not clear.

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ROLE MATRIX

Chart II-4

	Funder	Provider	Advocate	Protector	Monitor	Planner	Policymaker	Regulator
Legislature	•		•	•	•	•	•	•
DMH	•	•	•	•	•	•	•	•
Other State Agencies	•	•				•		•
Patients								
Families			•					
Provider Organizations		•	•			•		
Courts				•	•		•	•
Associations			•		•			
Citizens			•		•			
Local Boards	•				•	•	•	
Advisory Boards			•	•	•	•		

CHART II-4

PARTICIPANTS

Legislature: Both houses of the State Legislature and their mental health commissions

Department of Mental Health and Developmental Disabilities (DMH): Self-explanatory

Other State Agencies: Department of Public Health, Department of Public Aid, Department of Children and Family Services, Department of Corrections, Department of Registration and Education. Comprehensive State Health Planning Agency

Patients: Mentally ill and developmentally disabled clients whose treatment and care is the responsibility of the Department

Families: Of the patients

Provider Organizations: Community agencies, hospitals, and other organizations that deliver patient services

Courts: Self-explanatory

Associations: Organizations of citizens independently formed to promote the interests of a certain group of persons (e.g., Illinois Association for Mental Health, Illinois Association for Mentally Retarded)

Citizens: Unaffiliated concerned citizens (i.e., the general public)

Local Boards: Councils of community citizens formed to plan services and/or administer funds

Advisory Boards: Officially created statewide councils

ROLES

Funder: One who allocates and appropriates money

Provider: One who directly delivers services

Advocate: One who promotes a specific interest or proposal

Protector: Defender and guardian of individuals

Monitor: Critical observer

Planner: One who delineates a course of action over time to be followed in implementing policies and strategies

Policymaker: One who sets the goals, strategies, and standards to guide planning and service delivery

Regulator: One who defines the limits of policy and service delivery and sees that such definitions are adhered to

CHAPTER THREE: COMPREHENSIVE DELIVERY SYSTEMS OF LINKED SERVICES

The cornerstone of the Department's mental health and developmental disabilities goal is the *comprehensive delivery system of linked services.* In concept, we know what it means: for each patient in each community, an interconnecting array of all the services necessary to provide that patient with a continuity of care. Few people, however, have tried to describe what the system should look like in terms with which both professionals and lay citizens can deal:

What services?
How are they connected?
Where are the current system deficiencies?

These questions are the subject of this chapter.

A. MENTAL HEALTH DELIVERY SYSTEM

Chart III-1 presents a simplified diagram of a prototype community delivery system for mental health services, including drug abuse and alcoholism. Essentially, it presents the alternatives that should be available to each patient, depending on his diagnosis and needs. The services are differentiated according to whether the goal is to provide them in the community or at some state-operated facility. The arrows are the desired linkages among services. The one-way arrows indicate progression to the next service called for in a treatment plan. The two-way arrows are linkages among alternative services available to a patient at any stage in his treatment. Most of the service definitions are self-explanatory. More complete definitions can be found in the Department's *Guidelines for Grants for Community Programs.*

The system is presented regardless of whether the services are funded entirely or in part by Federal, state, or local sources. Twenty- two of the twenty-five identified services are to be provided in the community – or at least patients in those communities should have effective linkages to them in nearby communities. No community, however, need offer all twenty-two services. All are presented here only to indicate the available options. Services offered in each community will depend on an assessment of community population need. Furthermore, these are the service options possible within the Department's concept of community mental health, which addresses treatment and care of former state mental health patients and those persons in danger of being extruded from the community. Agencies desiring to offer other services to patients with more moderate conditions or preventive services would have to modify this model to reflect their programs.

It is safe to say that none of Illinois eighty-three planning areas (i.e., mental health communities) has fully implemented a comprehensive delivery system of linked services. Some are more developed than others. It is important to examine the weaknesses in order to concentrate our efforts to erase them.

The key to an effective community system is in the first three services: *emergency services, admission/screening,* and *diagnostic services.*[1] Over the years, mental health professionals have been criticized because some clients were misdiagnosed or assigned to improper treatment and care.

EMERGENCY SERVICES

Twenty-four-hour *emergency services* for crisis situations must be available. They can be offered in clinics, general hospitals, or other community facilities, and they must have immediate linkages to the ongoing delivery system (i.e., no one should be discharged from emergency services). Many

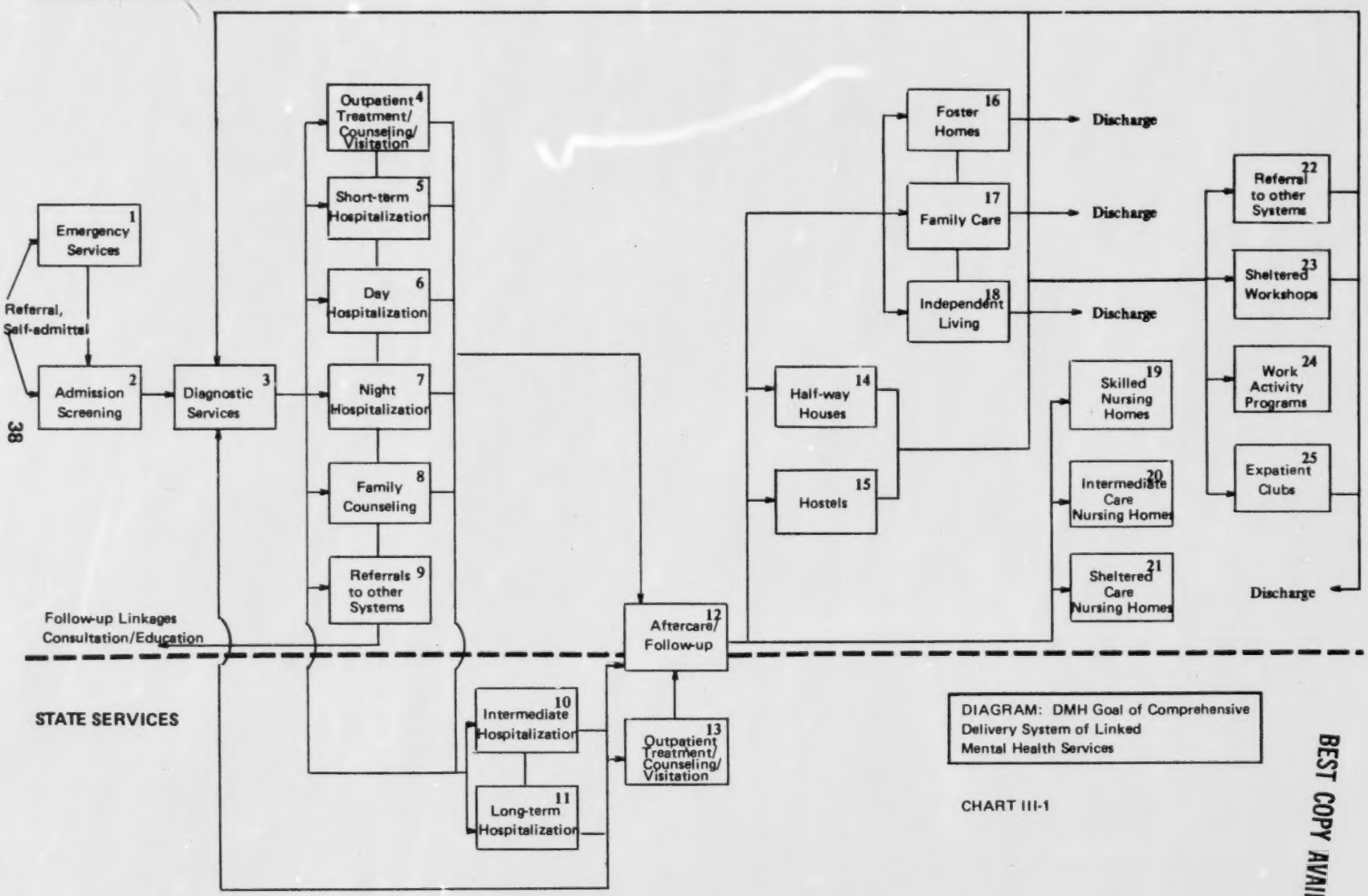

DIAGRAM: DMH Goal of Comprehensive Delivery System of Linked Mental Health Services

CHART III-1

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communities do not yet have emergency services available to all, and some that do are not effectively linked to the system. Moreover, some Department regional personnel have not given the development of these services a high priority.

ADMISSION, SCREENING, DIAGNOSIS

Admission of patients to the system, their initial *screening* in terms of their problem, and the problem's *diagnosis* (and development of an appropriate treatment plan) are vitally important to (1) ensure that the client is properly placed according to his need and (2) refer to state institutions only those patients for whom no community service would be adequate. Ideally, in each geographic area readily accessible to its residents there should be one agency for admission, screening, and diagnosis. This would ensure a single standard and equitable treatment throughout the area. In Chicago, for example, there is one preadmission evaluation center for the elderly, manned by a team of personnel from the Departments of Mental Health, Public Health, and Public Aid. The preadmission examination must be completed in seven days. Elderly clients with no marked mental condition have received appropriate non-mental health assistance and have not been inappropriately admitted to state facilities. Such a center should be examined by all communities for all populations.

It is not likely that, in the near future, each community will have a single *admission/screening/diagnostic* service center. If a state facility is nearby, the police and other professionals still direct the patient to that facility.[2] Furthermore, there are many mental health agencies in community delivery, and most are entry points into the system for persons who know of them. These agencies would be reluctant to give up this function. Nevertheless, in a fully developed delivery system a single community agency should at least have control over the admission/screening/diagnostic services to ensure equitable treatment and the single standard. Even that, however, would be difficult; without a communitywide mental health board, who would choose?

Some critics have observed that community *screening* and *diagnostic* services are not performed by an agency's most skilled and experienced personnel. Misdiagnosis and misplacement can occur. If proper *screening* and *diagnosis* are two of the most important parts of the system, an agency should probably assign some of its most experienced personnel to this function.

BASIC PROGRAM SERVICES

Much of the public criticism of comprehensive community delivery systems has been levied at the Department's handling of program services (4) through (9) on Chart III-1. It is charged that the Department is forcing these services on the community without adequate funding, training, or time to prepare adequately.

The Department admits that it has had to press some of these services on some communities. Its procedure is to budget for the transfer of institutional programs to the community; money will not be available to the institution, but only to the community through a grant-in-aid. Most community agencies agree to the transfer; some do not. The latter may have their total grant delayed until agreement can be reached.

While this is a tough stance, the Department argues that it is the only way to get some community agencies to serve the groups most in need of mental health services. As long as services better provided in the community are offered by state institutions, the tendency is that they will be used by the community.[3] Were community agencies to

propose to the Department realistic plans for initiating services to those patients in greatest need, the Department's stance might be softened.

Agencies also complain that adequate funding does not accompany the transfer of programs to the community. They say that while the direct service costs may be funded, applicable overhead costs are not, and the introduction of new programs administratively burdens their staffs. The Department says that regular administrative costs must be included in each program budget. If additional funds are available, special grants can be made for a separate administrative program so long as the agency itself agrees to fund a significant portion.[4] Inasmuch as overhead is generally not attributable to specific programs, it would probably be included in this special grant – for which funds are extremely limited.

As every community agency knows, negotiation for funds from another source is called grantsmanship. The applicant frequently overstates his goals, describes his capabilities in the most glowing terms, and tries to get the maximum dollars possible. Knowing this, the funder devalues the goals and capabilities and wants to spend the minimum amount in order to fund the maximum number of services in the area. The applicant and funder usually compromise somewhere in between. The Department is now in the process of minimizing grantsmanship by establishing staffing, achievement, and funding standards for different types of services. In the meantime, however, there will always be criticism that the Department does not adequately fund the services it wants delivered. There is no way to determine how justified the criticism is so long as grantsmanship is the game.

A more serious criticism of the Department is that, in funding community programs, it discriminates against community mental health programs established under HB 708. The state has relied on community funding to pay part of the costs of the services of some agencies, for treating those persons in greatest need (contrary to Department policy). This practice clearly must cease.

The Department will be paying more attention to Department/community interaction in new program initiation. Sometimes institutional staff moves with transferred programs. More often, however, communities develop and staff the programs themselves. Some agencies require technical assistance, while others may need nothing more than frequent encouragement and handholding. In some regions the Department/community interaction is much stronger than others, where Department personnel seem to resist the transfer of programs and patients to the community.

STATE INSTITUTIONS

As discussed in Chapter Two, state institutions have not yet become as integral a part of community mental health delivery systems as possible. They are convenient alternatives rather than complements to community systems. One reason, of course, is that the systems have not been fully developed. Incidents have been reported in which state institutions have rejected admission to persons referred by community agencies. The Department should spend considerable time with community agency screening and diagnostic personnel helping them establish standards for evaluating clients who are potential candidates for institutionalization.

AFTERCARE/ FOLLOWUP

In a fully developed community delivery system, aftercare and followup services for a patient discharged from a state institution should immediately be assumed by an appropriate community agency. In some instances they do. At Madden, for example, community agencies regularly

visit patients while institutionalized. They get to know the patient, are advised when discharge is imminent, and are prepared to work with the patient once he leaves the institution. In Chicago, on the other hand, there have been instances where patients have been discharged without the knowledge (much less the involvement) of community clinic personnel. For example, the Chicago Board of Health recently observed that patients previously discharged to Mid-South Hospital were now being placed in a private hospital (Mercy). The policy change wasn't communicated to the Board of Health; thus, it couldn't provide adequate followup.[5]

It is possible, of course, that Department discharges without community notification occur because local personnel do not provide adequate followup and aftercare services to former institutional patients. Nevertheless, it should be Department policy that – wherever possible – no patient discharge shall be made until an appropriate, capable community agency has agreed to provide the necessary aftercare.

When the Department places patients in community long-term nursing facilities, a Department staff member is mandated to visit them once a month for at least a year. Some facility operators complain, however, that they are visited and inspected by too many agencies (i.e., Department staff to see their former patients, Department of Public Health personnel for licensing purposes, Department of Public Aid personnel to see patients who are receiving public assistance). In the Springfield region these agencies are testing an inspection and visitation process whereby only the Department of Public Aid makes the visits. Special training in this pilot project is being provided for a new class of health professional, skilled and knowledgeable in the programs of the three Departments. Some groups criticize this effort, contending that Public Aid staff cannot provide adequate followup to former mental health patients. It is still too early to determine whether this test is effective and should be implemented statewide. The concept, however, is worth continued examination. With proper training, this new health professional can serve the needs of several agencies – with a resultant smaller burden on the facility operators and state agency staffs.

Some patients' families have criticized the Department because they have not been permitted to approve – or veto – a patient's discharge or transfer. They have been particularly upset when a patient is transferred from one facility to another more distant from where the family resides. The Department's position is that so long as a patient is its responsibility, it (and it alone) must ensure that patient's effective care and treatment. Were the family to veto transfer or discharge, the patient's rights to the most effective care and treatment (as well as his right to be out of an institution) could be abrogated. The Department would be liable to suit. Its policy, however, is *always* to consider the family's views prior to discharge or transfer. In practice, family *disagreement with the Department's action has been extremely rare.* Both want what is best for the patient.

CONTINUITY OF CARE

The patient must have access to all available services appropriate to his particular stage of treatment. He must not be lost in the system (i.e., the agency responsible for his treatment and care must know where he is at all times). Ensuring continuity of care is not an easy task in a system that involves services provided by many different community agencies and the state. It can be complicated by a client's movement from one part of the state to another. Effective continuity of care requires, therefore, support from sophisticated information systems compatible with all Department regions and all community agencies. Previously, there were

no statewide information systems. They are now being implemented by the Department. One system is concerned with hospital inpatients, providing up-to-date statistics of all hospital movements for *each* patient. Another will provide statewide, comparable data on clients in state-operated outpatient facilities and day-care centers, state-aided facilities, long-term care homes, and general hospitals and private sanitaria. Currently designed to provide information on how staff time is spent, the characteristics of the facilities' caseloads, and staff/caseload relationships, it will eventually include financial data by program, diagnosis, age group and geographic area.

The Department also has a management cost system providing basic information on the number, costs, and charges for patient days and contacts and for special services rendered to patients. The system can provide comparable cost data for each organizational element.

B. DEVELOPMENTAL DISABILITY DELIVERY SYSTEM

Chart III-2 presents a simplified diagram of a prototype community delivery system for developmental disability services. As with the prototype mental health system, it presents the alternatives that should be available to each client, depending on his diagnosis and needs. The services are differentiated according to whether they are to be provided in the community or by the state. The arrows are the desired linkages among services. More complete service definitions can be found in the Department's *Guidelines for Grants for Community Programs.*

Many of the deficiencies in developing comprehensive delivery systems for mental health are also present in developmental disabilities. Criticism is that the Department relies prematurely on community alternatives to institutional care, that adequate funding does not accompany the transfer of programs to the community, and that there is insufficient Department/community interaction in program development. Over the past year, however, the Department has made significant progress in improving the treatment, rehabilitation and care of the developmentally disabled.

PLACEMENT The developmental disability delivery system does, however, have its own problems. For example, a fully implemented system will have the casefinding/ information/referral service provided in the community. The Department is now placing *three* clients in a community facility for every *one* placement made by the community referral service. Communities tend to rely on the state-operated program as a primary casefinding and referral service. The Department's five-year goal is to reverse the current practice: i.e., it should place *one* client in a community facility for every *three* placements made by the community. Reversing this practice will require substantial expansion of community resources, with the state residential facilities reserved for the profoundly retarded, nonambulatory patient.

CASEFINDING There is disagreement as to how many people are mentally retarded. Some organizations contend that 3 percent of the population is mentally retarded. Department professionals say that the figure is closer to 1 percent.[6] Some citizen organizations have criticized the Department for statistically eliminating 200,000 mental retardates. This debate, however, begs the central concerns: who among the

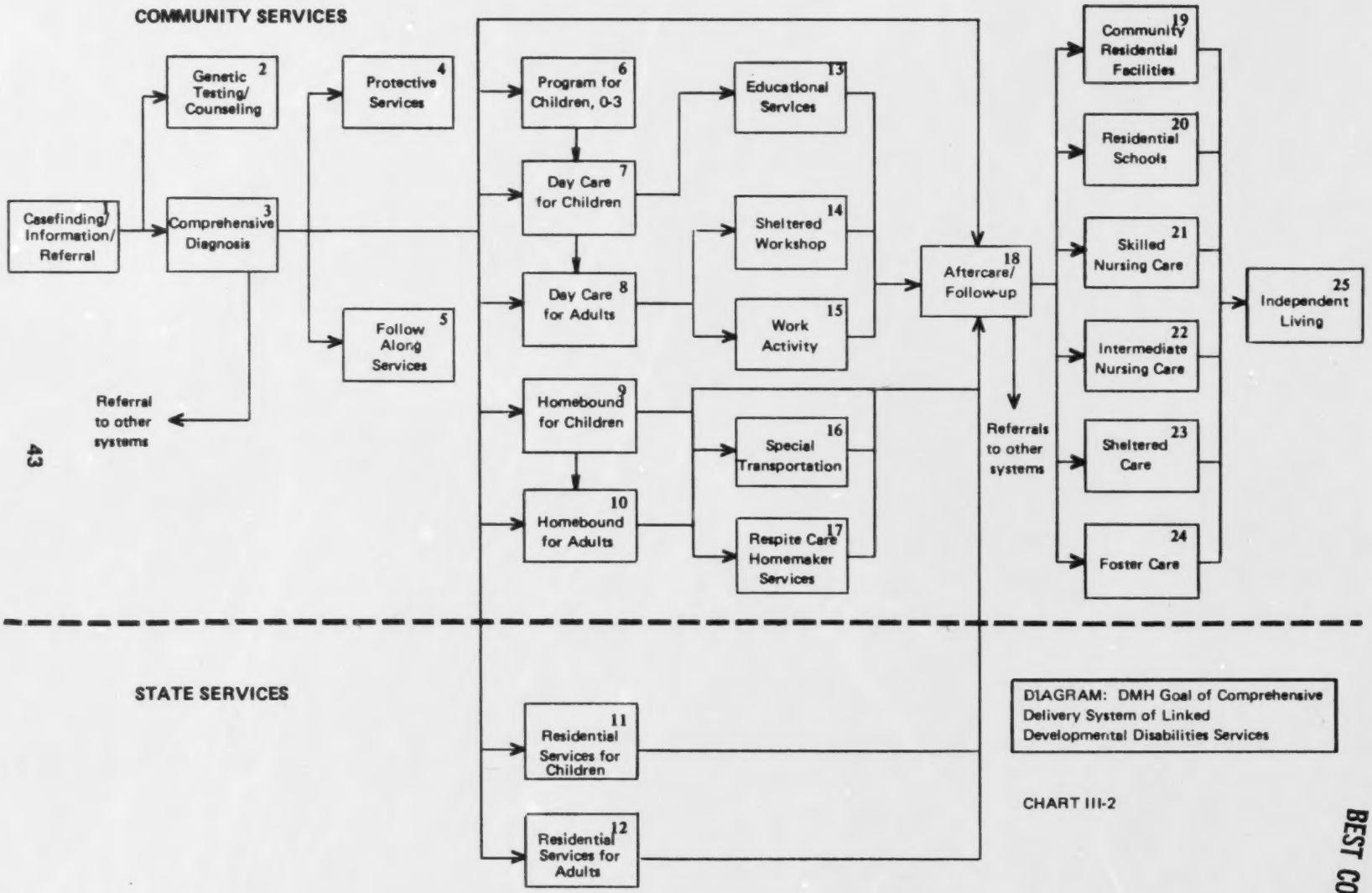

DIAGRAM: DMH Goal of Comprehensive Delivery System of Linked Developmental Disabilities Services

CHART III-2

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mentally retarded *need state-operated or state-supported services*, and what is the *most effective treatment* for those in need?

As community casefinding and information services in developmental disabilities expand, more potential clients in need will be found to demand services. The potential number of clients in need becomes relevant so that both the state and community agencies can budget for them services to provide the most effective treatment.

EDUCATION

Mentally retarded school-age children represent the great majority of developmentally disabled persons receiving publicly supported treatment. Illinois state law assigns to school districts the responsibility for educating *all* children, regardless of their disability (see Services Number 13, Chart III-2). These districts are reimbursed for the educational services they provide for the mentally retarded. *School district* education of the mentally retarded is an important component of the Department's program – to enable the children to enjoy, to the maximum extent possible, normal and productive lives in their communities. This goal is constrained when mentally retarded children must be educated in an isolated institutional setting. State law also provides, however, that if school districts do not provide the necessary educational opportunities for the mentally retarded, they must reimburse the agency providing those opportunities.

The positive intent of the state law is not disputed. Its implementation has constrained the Department, mentally retarded children, and their parents. *First*, the education system in the state is fragmented. *There are 1,183 independent boards of education in Illinois;* it is truly impossible to negotiate satisfactory agreements with each of them.[7]

Second, financial capability constrains the majority of districts. Frequently the special educational requirements of the mentally retarded require more money than the districts receive from the state. They tend to reimburse the Department of Mental Health and Developmental Disabilities or private facilities for these educational services because of a reimbursement ceiling. Legislation is now being considered to increase the maximum amount that districts may be reimbursed for providing these educational services themselves.

Third, many districts lack the teacher skills to meet the specific educational needs of the mentally retarded. Larger districts can hire specially trained personnel. Smaller districts are in the majority, and the number of mentally retarded children in their communities may not be sufficient to justify hiring specially trained personnel.

Fourth once school districts assume this educational responsibility, many are reluctant to turn to the Department of Mental Health and Developmental Disabilities and other agencies for the advice and training they need to operate effective programs. Professional jealousy is powerful and demoralizing.

Fifth, some school districts have found ways to bend the law's intent to the detriment of mentally retarded children. Some have recognized that there is no effective way to enforce it – and they have ignored it. To our knowledge, *none* have been taken to court. Others have been more devious. For example, if they *"graduate"* a student, they are no longer responsible for his education.

Sixth, many parents oppose school district assumption of the educational responsibility for their mentally retarded children. They have little confidence in the educational system for normal children and would much prefer that the Department, which is specifically interested in their children, provide the necessary educational services.

All six of these concerns are legitimate. They constrain the effective treatment, education, and rehabilitation of children who could live relatively productive and happy lives in their own communities. A comprehensive delivery system of linked developmental disability services in each community will not be a reality until each of these concerns is resolved.

EVALUATION While evaluation of the effectiveness of all mental health and developmental disability programs is difficult, it is perhaps harder for the developmental disabilities. The majority of cases are likely to be more acute, and progress is measured in years rather than weeks or months. Most mentally ill patients can be restored to some degree of normal functioning; most developmentally disabled clients (moderate, severe or profoundly retarded) can be habilitated to live relatively satisfactory if constrained lives.

Unfortunately, some professionals tend to downplay evaluation of alternative methods of treatment, rehabilitation, and care.[8] The developmentally disabled *require* assistance; almost any type of treatment is better than none at all. While recognizing that improved evaluation of alternatives is essential, the Department is committed to seeing that the lack of such evaluation does not cause services for the developmentally disabled to suffer in their competition with other programs for public dollars.

CHAPTER FOUR: PROBLEMS OF SPECIAL POPULATIONS

In the delivery of mental health and development disability services, children, the elderly, and forensic clients (those under the jurisdiction of the courts) pose special problems. They are the subject of this chapter.

A. CHILDREN

There is some evidence that, both nationally and in Illinois, children (17 years of age and younger) receive proportionately less treatment and care than do adults. Nationally, this age group accounted for 40 percent of the general population in 1969, but they represented only 26 percent of the admissions to Federal comprehensive community mental health centers.[1] Statistics for 1973 for Illinois reveal that children were 33 percent of the state population but accounted for only 21 percent of the episodes at state and community mental health facilities. The majority of these episodes were treated in community outpatient clinics.[2]

There are several reasons why it appears that children and adolescents do not proportionately receive the services that other age groups do. *First*, to the extent that mental health services are provided to protect the community (as well as treat the patient), mentally ill adults are seen as a greater threat. While the Federal Community Mental Health Center legislation emphasized equal treatment for children, it took legislative amendments in 1970 to earmark funds for special children's programs, recognizing the previous lack of such programs.[3]

Second, mental health professionals are extremely reluctant to institutionalize children, fearing that it will give them a stigmatizing label that may do them a disservice for the rest of their lives. Thus, in the absence of effective community programs, children are not served adequately. Quoting from the report of the Joint Commission on Mental Health of Children, Glasscote reports:

> *".....even at present there is no community in the United States which has all the facilities for the care, education, guidance, and treatment of (emotionally disturbed or mentally ill) children. The few services which are available are poorly coordinated and are usually unavailable to poor and near-poor children."*[4]

This fragmentation of services is extreme: if the child needs medication, individual therapy, remedial education, and family casework, the family may have to take the child to four different agencies – and the child must relate to four different groups of people.

Third, there is a severe lack of professionals qualified to treat children. Citing the Joint Commission on Mental Health of Children, Glasscote notes that if all seriously disturbed children in the nation were treated in residential centers or on day status, using a team approach with caseloads of fifty children, we would need six times the current number of child psychiatrists, more than the entire population of clinical psychologists, 18,000 social workers, and 27,000 psychiatric nurses nationwide.[5] Many mental health professionals point out, however, that these disciplines may not be necessary to treat children effectively. There is *no evidence* that the number of child psychiatrists has anything to do with the quality of care. Nevertheless, appropriately trained personnel are in short supply.

Fourth, parents and teachers do not fully understand what constitutes mental illness and emotional disturbance in children. Initially, mental illness in young people is often seen as mental retardation or problems not with the child but with the family or the education system. Children may ultimately be brought for help only when the risk of institutionalization is great.

In order to provide effective treatment and care of children and adolescents, the guiding principle of the Department of Mental Health and Developmental Disabilities is that all programs must include treatment, education, and rehabilitative services necessary to promote individual growth. The child's overall development is the primary concern. Specifically, the Department says:

- All services for children and adolescents must, whenever possible, be family-centered because development normally occurs within a family structure;
- Services should primarily be community-owned, and the Department will support them with financial and manpower resources;
- Mental health services are only a part of the total services required by children, and a single agency must assume responsibility for ensuring that the child's major life requirements are met;
- There must be someone to speak for the child as an advocate or spokesman;
- *Services should be less on a program-categorical basis (e.g., mental health, education, guardianship) and more in terms of a comprehensive range of services applicable to child and adolescent needs.*[6]

The obvious question, in light of limited resources, is: which children should receive priority consideration for treatment supported by state funds? Overall Department policy is to treat and care for former mental health patients and those persons in danger of being extruded from the community. This policy is more difficult to apply to children. *First*, inappropriate educational services in the community immediately place the child in danger of some form of institutionalization. *Second*, it may be that children in families with a history or current incidence of mental illness should also receive priority consideration under the assumption that the risk of emotional disturbance to the child is greater. *Third*, early intervention with the child, when the disturbance may be less severe, may help prevent serious mental illness when he becomes an adult – when the state will be forced to provide for his treatment and care. These are not easy problems to resolve, because there is no agreement as to what less severe conditions in children may lead to extremely severe disturbances as adults. The present Illinois Mental Health Code does not single out children. Whether or not the current code revision[7] addresses the specific problems of children, it must define *"mentally ill"* and *"emotionally disturbed"* children and adolescents in terms that can be agreed upon in developing, implementing, and defending the services that are to be offered to them.

Interpreting Department policy, it seems obvious that the key participants in the delivery of services to children are *parents* and *teachers*. Glasscote observes:

"When mental health professionals are outnumbered by school teachers in a ratio of perhaps twenty to one, it seems evident that the longer-term goal should be one of augmenting the education of the schoolteacher.....so that he or she will have an adequate understanding of children, their problems, and their development."[8]

This observation might apply equally well to parents. As pointed out in Chapter Three, the Department has had significant problems in arousing the education system to assume responsibility for disturbed children. The Department should not have to play this advocacy role. Because it also delivers mental health and developmental disability services, persons in the education system might see the Department's role as primarily one of trying to avoid part of the responsibility for treating emotionally disturbed children. It would be better if another agency – one not responsible for the delivery of mental health services, such as the Department of Children and Family Services – were to assume this advocacy role with the education system – and with children's parents.

B. THE ELDERLY

In 1970, 961,000 persons 65 and over in the United States lived in institutions, or about 5 percent of the elderly population. It is estimated that while the proportion of this population group will increase by only 0.3 percent over the next 50 years, the number of people in institutions will double. Of these 961,000 persons, 74 percent were in nursing homes, 12 percent in mental hospitals, and 14 percent in all other types of institutions. In 1969, there were 1.5 million beds in specialized medical hospitals and nursing care facilities: 62 percent in nursing care and related facilities, 32 percent in psychiatric hospitals, 3 percent in geriatric hospitals, and 3 percent in other types of facilities. Eighty-nine percent of nursing home patients and 28 percent of mental hospital patients were over 65 years of age.[9]

These statistics cover the elderly institutionalized for all types of disabilities – mental illness being only one. Not surprisingly, a 1972 survey by the National Institute for Mental Health described almost all elderly patients in mental hospitals as having a serious mental condition: 36 percent schizophrenic who have been in mental hospitals most of their adult lives, and 45 percent organically disturbed (e.g., arteriosclerosis, senility, or the effects of drugs, alcohol, or syphilis).

Surprisingly, however, the 1973 national survey by the National Center for Health Statistics revealed that *more than half* of the elderly in nursing homes suffer from a mental condition – 62 percent from some stage of senility.[10] Translated to Illinois, if we assume that the majority of nursing home residents are elderly, then approximately half of the 66,000 residents have some mental impairment, while less than one-quarter (17,000) are former Department patients.

Analysis of the above statistics produces some important issues that must be addressed in treating and caring for the mentally ill elderly.

First, the nursing home is now – and will likely be in the future – the primary resource for the institutionalized elderly, including those with mental conditions. State mental hospitals do not have the beds to care for *all* mentally ill persons, nor in recent years have they done so.

If we believe the national survey, more than three times as many elderly with a mental condition were residents of nursing homes as opposed to mental hospitals. In Illinois there are 17,000 former Department patients (mostly elderly) in nursing homes, only 2,000 elderly patients in state facilities, and another 3,600 treated in community outpatient clinics.[11] Thus, efforts to improve the quality of care and treatment of the elderly *must be directed* to these community facilities.

Second, we must be clear on what constitutes mental illness of the elderly. Obviously it includes the normal symptoms for diagnosing conditions in other age groups. But does it also include forgetfulness and senility? The Department's position is that for former institutional patients, it does. The Department will not abandon any of its former patients because their only symptom is senility. However, in screening and diagnosing new clients, the Department believes that senescence or forgetfulness alone does not constitute mental illness. While recognizing that senile individuals do require protective care, it does not believe that their care should be provided under mental health auspices. It should be stressed that the Department's position does not affect the care of the low-income elderly who have a senile condition: both Medicare insurance benefits and Medicaid assistance payments are available to them for appropriate institutionalization.

Third, what mental conditions of the elderly are best treated in state institutions, and which are best treated in community facilities? Generally, the conditions for institutional care are the same that apply to the rest of the population: schizophrenia, manic depressive psychoses, major acting out disorders, suicidal depressions, severe organic brain disease. Elderly patients with schizophrenia may be easier to treat than lower age groups in the community because research has shown that the disruptive manifestations of this disorder are substantially arrested for senior citizens, and the need for medication may be less. Currently, however, 38 percent of the elderly patients in state facilities suffer from schizophrenia – the largest single diagnosis of this age group.[12] A major criticism by community organizations has been that elderly patients who have resided in state facilities for a long period of time have been inappropriately discharged. While conceding that many of these elderly patients should never have been institutionalized in the first place, it is argued that it is unfair to separate them from institutions that have become, in effect, their homes. Moreover, it is believed that this disorientation may cause premature death. The Department has no evidence to support the *"higher death-rate"* theory. In 1973, 29 percent of the discharged elderly patients had been residents over 10 years (contrasted with 33 percent who had been residents less than 60 days). Discharge of this 29 percent was made under the Department's clinical judgment that these patients could receive as effective care in nursing homes or other long-term care facilities.

Fourth, if primary care for the institutionalized elderly is to be in nursing homes, what kind of care and treatment are required? And how will they be provided? This is, in some respects, the most volatile of all the *"elderly"* issues. As discussed in Chapter Three, there are problems. In many nursing homes, treatment is minimal and rehabilitation and activity programs are deficient – even though the homes are licensed. In implementing the new Federal standards for nursing homes, however, the Department does intend to reward financially those home operators who provide a higher quality of treatment and activity. It should be emphasized, however, that the issue of quality nursing home care is much broader than for only former Department patients. Were the Department to apply more rigid standards only to its former patients (which is all it could legally do), then 75 percent of the nursing home residents would be discriminated against (and one-third of those have been

diagnosed as having some mental disorder). Indeed, because of the makeup of most homes, more rigid Department standards would have to apply to all the patients. Thus, it is not only for the Department of Mental Health and Developmental Disabilities to decide; it is an issue for the broader community. The only alternative would be for the Department to place its patients only in homes reserved entirely for them, which is clearly not salutory for patients.

C. THE FORENSIC CLIENT

Every individual judged *"unfit to stand trial"* or ciminally insane by the criminal justice system is assigned to the Department of Mental Health and Developmental Disabilities for custody and treatment until the mental condition has been removed. All such patients are treated in state facilities – the most dangerous at the Chester Mental Health Center (formerly the Illinois Security Hospital). In 1974, the new Chester Facility will be opened to permit expansion of programs for the forensic client. In 1973, approximately 2 percent of the state's institutional residents were at Chester.[13]

Treatment and care must necessarily be contrary to the Department's goal of treating patients, to the maximum extent possible, in the community. The potential threat to the community and the court requirement for the patient's confinement override treatment considerations. This is as it should be. However, it must be pointed out that many of these forensic patients have disorders that, but for their incarceration, would be treated in the community. In a maximum security setting they are not receiving the most effective treatment.

When a court assigns a person to the Department, the Department must concur that the client has a mental condition for which institutional care and treatment are required. If there is no concurrence, the person is sent back to the court for alternative custody. However, there may have been several instances in which a judge has refused to abide by the Department's determination and has demanded that the Department assume custody. These instances usually occur prior to trial and are used to circumvent the person's right to bail. They are clearly an abridgement of the person's rights and could cause him damage because of unnecessary mental institutionalization.

Once the Department assumes custody, it determines whether the client should be assigned to the Chester Mental Health Center or another appropriate facility. Recently there has been at least one instance in which clinical judgment has been overriden by administrative concern. Because of a specific incident at Manteno State Hospital threatening the safety of members of the staff, Manteno is no longer considered an alternative to Chester for less dangerous patients. While safety of the staff must be a primary concern, one incident (or even a few) does not seem to justify a policy change to the ultimate detriment of the patients.

Treatment and care of forensic patients are relatively minor parts of the Department's program, so it is understandable that they do not receive significant attention. However, many of the deficiencies do involve the patient's rights – something that should be addressed by the Department, those advocacy groups representing the forensic client and the Governor's Commission for Revision of Mental Health Code of Illinois.

CHAPTER FIVE: MENTAL HEALTH AND DEVELOPMENTAL DISABILITY PLANNING IN ILLINOIS

The general role of planning in the development and delivery of mental health and developmental disability services was discussed in Chapter Two. The purpose of this chapter is to examine more closely the planning issues in Illinois and to propose how they might be most effectively addressed in planning for the full transition to community-based comprehensive delivery systems of linked services. This chapter begins with the assumption that all participants agree that substantial planning is required for the most effective and orderly transition.

A. THE CURRENT STATE OF PLANNING

Even though many state and local agencies are *responsible* for mental health planning in Illinois, the Department is the only agency that can effectively *do* any planning. It dominates service delivery and has the financial and staff resources to commit to planning. The Illinois Mental Health Planning Board, which has the legislative mandate for long-range planning in Illinois, has insufficient financial and staff resources. It has, therefore, concentrated on planning *issues* but not planning itself. The Comprehensive State Health Planning Agency also has responsibility for mental health planning in relation to health planning, and its mandate is to cover the entire state with regional and subregional health planning councils. By agreement, the agency has made the Illinois Mental Health Planning Board a component planning group for mental health. Progress has been slow. There have been difficulties in blanketing the state with these planning councils, and the Agency has concentrated more on *issues* of comprehensive planning than on the planning of the necessary systems.[1]

Community boards (e.g., established under HB 708, SB 377, and SB 553) are also responsible for mental health system planning, but they have rarely been given sufficient funds to do so. In a way, their planning role has become more reactive than active – i.e., approving, disapproving, or commenting on agency requests for financial assistance.

Individual provider agencies are also responsible for mental health planning, but it is normally limited to single-year operational plans for delivering the services proposed in a grant request. These agencies are primarily concerned with their own services and not necessarily how they link into a total system.

Thus, one might describe mental health planning in Illinois as

- Dominated by the Department of Mental Health and Developmental Disabilities, whose long-range planning function seems to be legislatively given to the Comprehensive State Health Planning Agency and the Illinois Mental Health Planning Board
- Fragmented among many agencies at different governmental levels
- Complicated by the intervention of various Legislative commissions

- Filled with gaps at the local level because of the uneven development of regional and subregional councils and the absence of mental health boards in many communities
- Lacking sufficient state and local funds to do adequate planning
- Concentrating on *issues* of comprehensive mental health planning rather than on the *system* itself

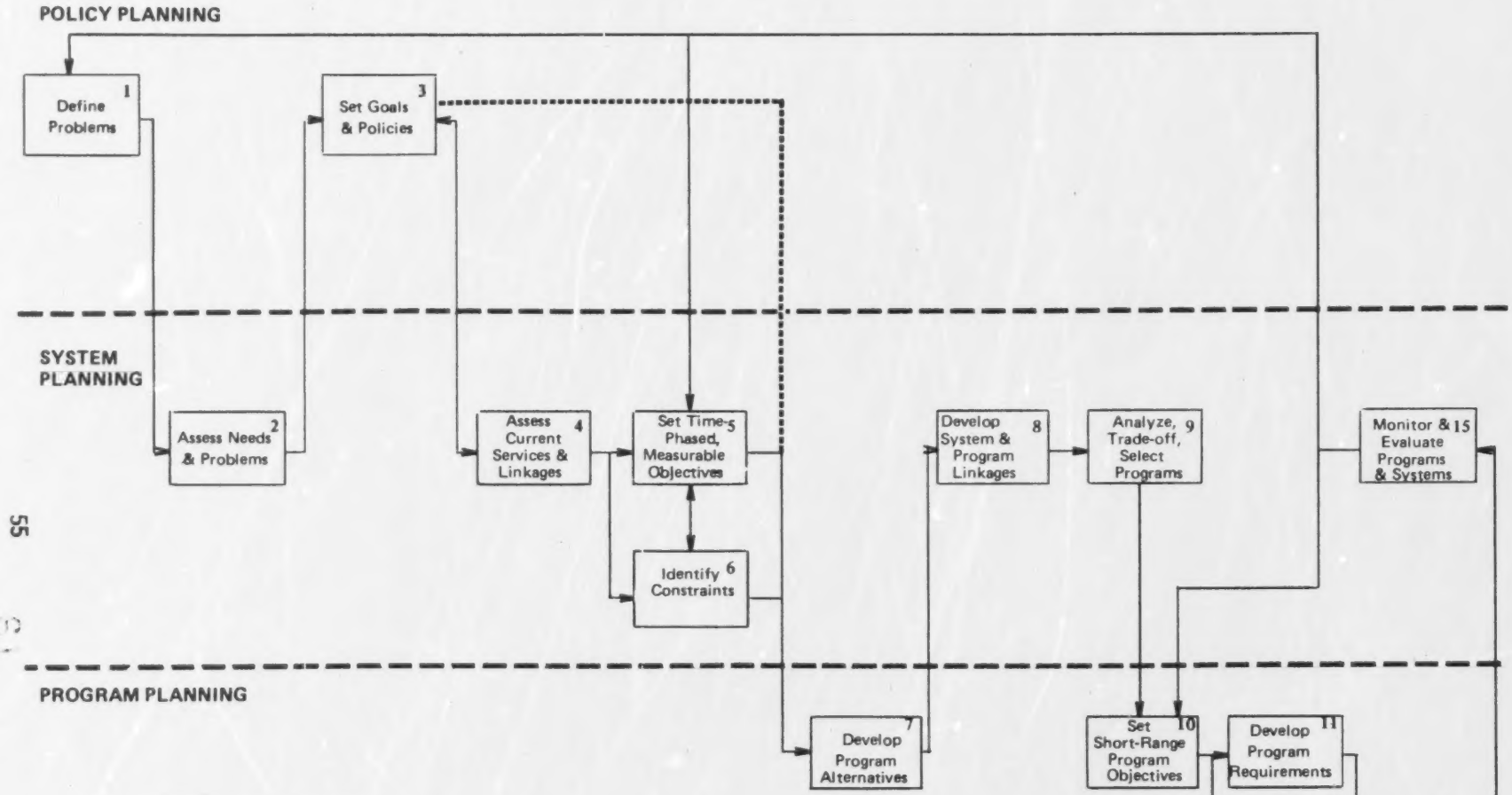
Small wonder that there has been little comprehensive mental health planning in Illinois.

B. A PROTOTYPE PLANNING MODEL

Chart V-1 presents a simplified model for the planning of comprehensive mental health and developmental disability delivery systems. The model is intended to be applied statewide, regionally, by communities, and by specific agencies.

The first distinction to be made is that there are three types of planning: *policy, system,* and *program. Policy planning* is defined as the process of determining the problems, goals, implementing policies, standards, regulations, priority target populations, and necessary program services. It is a first step for each agency responsible for delivering or funding services. Similarly, it is a first step for any coordinating board or agency responsible for planning and/or approving services in its area of jurisdiction. *The Department of Mental Health and Developmental Disabilities is the only organization in the state that has consistently engaged in policy planning,* although some would argue that its policies have not always been consistent and understandable. It should be emphasized, however, that the Department's policy planning relates only to the delivery and funding of its program services and does not necessarily apply to the services of other organizations. As a practical matter, of course, the Department's policy influence is dominant. The Comprehensive State Health Planning Agency and its component agency (the Illinois Mental Health Planning Board) have also undertaken policy planning, but their policy influence on service delivery has, to date, been minimal.

System planning is defined as the process of assessing needs and determining the program service linkages that are most effective and efficient in providing clients with continuity of care. It must primarily be undertaken by organizations responsible for coordinating service delivery within a specific community (currently in Illinois this would be each of the eighty-three planning areas and, if appropriate, subareas). Unfortunately, there is no such organization in each planning area. There are individual (and occasionally multiple) counties, municipalities, and townships that could assume the responsibility because of their mandates under the HB 708, SB 337, or SB 553 legislation. Most do not. The proposed regional and subregional councils under the Comprehensive State Health Planning Agency might do system planning, but they have not been fully developed. Therefore, the Department of Mental Health and Development Disabilities has done what little system planning there is. It has begun to assess community needs, evaluate program service proposals in relation to those needs, and try to ensure appropriate linkages as a condition of funding. It is extremely difficult, however, for a state agency (even with regional offices) to set time-phased, measurable objectives for accomplishment and plan for the most effective system of delivery in each community. Personnel just do not know the community well enough. Initiation of the regional citizens' advisory councils for community mental health services will help, but their primary role will not necessarily be planning.


POLICY PLANNING
Define Problems 1
Set Goals & Policies 3
SYSTEM PLANNING
Assess Needs & Problems 2
Assess Current Services & Linkages 4
Set Time-Phased, Measurable Objectives 5
Identify Constraints 6
Develop System & Program Linkages 8
Analyze, Trade-off, Select Programs 9
Monitor & Evaluate Programs & Systems 15
PROGRAM PLANNING
Develop Program Alternatives 7
Set Short-Range Program Objectives 10
Develop Program Requirements 11
Develop Capital Requirements 12
Develop Admin. Requirements 13
Implement Program 14

PROTOTYPE PLANNING MODEL
MENTAL HEALTH AND
DEVELOPMENTAL DISABILITIES

CHART V-1

BEST COPY AVAILABLE

Program planning is defined as the process of identifying the alternative program services possible within the system and, once selected, setting annual objectives for accomplishment, developing program financial and staff requirements, and preparing a work program for implementation. Program planning is undertaken by every provider agency for each of its program services. Although occasionally over-ambitious in terms of expected achievement, program planning is probably the most effective of any mental health and developmental disability planning. It is the most concrete and the most under control by the provider agency. It is limited in its usefulness to the comprehensive delivery of services, however, because of the deficiencies in system planning.

System planning should be the priority area for concentration.

C. ORGANIZATIONAL REQUIREMENTS FOR PLANNING

We start with the assumption that mental health and developmental disability planning in Illinois must be done as part of comprehensive *health* planning. Some people contend that this gives mental health too much of a "medical" cast, and they would prefer mental health planning to either stand alone or be a part of broader planning for all human services. The state policy, however, has already been set with the creation of the Comprehensive State Health Planning Agency and its mandate to include mental health.

While the State Legislature has assigned long-range planning in mental health to the planning board, this seems inappropriate – particularly as the board is currently constituted.

The most effective organization at the state level might be more obvious if we begin with the most effective organization in the community. The state must make it *mandatory* that every community establish its own autonomous mental health board. Current legislation is *permissive* for different levels of governments (counties, municipalities, townships). While appropriate to most of the state, Cook County (because of its size and complexity) probably requires smaller jurisdictions. The Department must either redefine its concept of community in terms of county or make certain that its planning areas are at least consistent.

When such boards are fully functioning and have completed their initial system planning, it should be Department policy that all grants-in- aid requests in the area go to the board for review and recommendation. The Department should fund agencies contrary to board recommendations only under extraordinary and well-defined circumstances.

Because of the regional planning concept in Illinois for mental health and other human services (seven regions), there should also be regional councils – primarily made up of representatives of each county board – to make certain that systems within the region are compatible.

At the state level, the Department and the community should have primary roles in policy and system planning: the Department as the dominant force in the delivery of mental health and developmental disabilities in the state, and the community as the primary provider and supplemental funder of those services. If the Illinois Mental Health Planning Board is to remain the primary agency at the state level, the Department and the community should have major roles in order to influence the course of planning. It must be obvious that so long as the dominant force (the Department) remains a relatively minor participant in overall state mental health planning, no other agency will have much influence.

Such an organizational system requires resources: money and staff. *Voluntary board representatives, without paid staff, cannot plan; they philosophize.* While the state must allocate more money to the planning function, communities must do so as well. It is to their advantage to make certain that their comprehensive systems of services are adequately developed and justified.

CHAPTER SIX: SUMMARY

The delivery of mental health and developmental disability services in Illinois has been under attack for years. Vocal interests believe the Illinois Department of Mental Health and Developmental Disabilities is altering patient treatment and care for fiscal rather than clinical reasons. They cite as justification for their belief the continued depopulation of state institutions, the proposed closure of more facilities, the *"abandonment"* of some groups of patients, the reduction of Department employees, the insufficient increase in grants-in-aid to community clinics, the limitation on state funds to treat primarily those patients most in need, the *"blackmail"* of community agencies to undertake previously state-operated programs, and the lack of any long-range planning.

These interests have consistently supported, at least in principle, the nationwide and Illinois goal that mental health and developmental disability services should be delivered to patients in the communities in which they reside. In criticizing the Department for its methods in trying to achieve this goal, however, these interests have not sufficiently recognized that

- Illinois record in transitioning to community-based services has not differed significantly from the national record as a whole: if the primary reason for the change is fiscal, then the blame must also be laid at the feet of the Federal Government and most other states.

- The transition from a tradition-laden, century-old institutional system to the community is complex, difficult, and inevitably filled with errors; change is painful.

The public's concerns are real and must be addressed. But if all continue to believe in the overall goal, these concerns must be approached in a manner to facilitate the uncompleted transition.

In reality, the public concerns are more complex than the specifically articulated issues. The active participation of lay citizens in a field dominated by mental health professionals for over a century is a recent phenomenon. Except for periodic exposes of deplorable institutional conditions, the general public has historically trusted psychiatrists to care for the mentally ill. Today psychiatrists and their mental health colleagues are being severely criticized by a lay public. They see their professional credentials under attack. It is not an easy pill to swallow. The delivery of mental health and developmental disability services in the community, however, opens the door to participation by a broader constituency: families who, in earlier days, rarely saw their patient relatives; independent provider agencies; and citizens concerned about maintaining a certain quality of life in their communities. All now have a direct stake in the delivery of services. Mental Health professionals must recognize and respect their interests. Members of this broader constituency must recognize that the mental health profession sees them as interlopers to the system. To participate effectively and positively, rather than hostilely, they must respect the expertise of the profession. The requirement is mutual trust.

In a publicly operated system today, however, such trust may take a while to develop. National political developments have caused citizens to distrust most governmental institutions. The Department of Mental Health and Developmental Disabilities may in part be an unfortunate victim of this pervasive national mood. It even permeates the Department, where far too much time is spent on responding defensively to public criticism rather than on the offensive – developing the community systems that everyone seems to

want. Such criticism is essential to the control of public programs, but at times both the critics and the defenders appear to lose sight of their common goal: the effective treatment and care of persons in need.

Some of the criticism is due to the state of the transition. Begun in 1960, the elements of the community system are in place. The current Department administration has been bequeathed the legacy of completing a system of care initiated fifteen years ago. There are no longer 47,000 patients in isolated state institutions. There were only 15,000 in mid-1974. Some of the remaining patients should be transferred to community services, but some will be hard to place. Some communities will be reluctant to absorb them. Errors will be made. The goal of community mental health may be questioned.

Some communities may be reluctant to commit their limited financial resources to mental health if they continue to believe that the Department wishes to shift financial responsibility to them. Chu and Trotter observe:

> *"Historically, local governments have relied on the state to provide most mental health services; and everything else considered – the needs in education, housing, transportation, physical health care – mental health (particularly as a separate system) is not among their highest priorities. Furthermore, local gvernments, with relatively narrow and inflexible tax bases, could not begin to meet the expenses of the program even if it were a high priority."*[1]

All of us are apprehensive, and we will criticize most every action. *Planning for the period ahead requires the closest positive collaboration of all system participants.*

Illinois poses significant problems in completing the transition of the delivery of mental health and developmental disability services to a comprehensive system in each community. Other states have defined mental health communities and required that they plan and deliver the services to their residents. Illinois has not. *Community systems will never be developed so long as the Illinois legislation is only permissive and the Department must deal independently with hundreds of provider agencies.* The heavy Department financial commitment to state facilities is another constraint on the development of these community systems.

The Department has historically consisted of seven mini-agencies, one for each region. While decentralization of such a large department is necessary, regional and institutional administrators have had wide latitude in interpreting Department goals. There are differences in the attitude towards community services, the evaluation of grant requests, the acceptance of community patient referrals for institutionalization, and the treatment and care of institutionalized patients. The Department must continue to develop adequate financial and treatment standards. Communities are understandably confused and upset about Department policies. They are insecure; they feel that they have no assurance that policies will not be changed or reinterpreted in succeeding years to jeopardize their clients, their staffs, and their programs. Problems abound.

But so do the strengths of mental health and developmental disabilities services in Illinois. All participants agree on the goal (rather unusual in human service delivery). The State Legislature has given mental health one of its highest priorities (again, unusual in comparison with other states). Communities continue to pass local referenda to tax themselves for delivering mental health services despite the criticism of the Department. The extreme abuses of patient treatment and care have been eliminated. The time is ripe to build collaboratively on these strengths to complete the transition to systems of community-based care.

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CHAPTER ONE

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2. The number of patients in residence or on active rolls at the beinning of the year, plus all admissions.

3. Defined as those services not requiring patient residency.

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5. National Institute of Mental Health, *Age, Sex and Diagnostic Composition of Resident Patients in State and County Mental Hospitals, U.S. 1961-1970,* Statistical Note 72 (Washington, D.C.: 1972), Table 1.

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16. Loc. cit., pp. 85-88.

17. Loc. cit., pp. 83-84

18. Illinois Department of Mental Health, *Mental Health Statistics for Illinois*, Fiscal Year 1973 (Springfield: 1973).

19. Comparable statistical data is difficult to obtain and, because of different reporting techniques, the data itself may not be totally comparable. To illustrate the point, Chart I-3 compares the national picture and Illinois, California, New York, and Kentucky in terms of three different fiscal years, spanning five years. This was the only comparable data available. Precise comparisons, therefore, must be qualified because of the rapid change in the delivery of mental health services. Chart I-3 should be used only to *indicate* where Illinois *probably* stands.

20. The adequacy and distribution of state funds to community programs will be addressed in Chapter Three.

21. Illinois Department of Mental Health, *A Review of the Fiscal Year 1973 Budget Request*, op. cit.

CHAPTER TWO

1. While it has been clear for some years that this has been the direction in which the Department has been moving, this goal statement is one of its first public articulations. It was developed from discussions with Department executives.

2. Illinois Department of Mental Health, *A Statement of Program and Policy*, June 1, 1969.

3. Loc. cit., p. 6.

4. Interview with Dr. LeRoy P. Levitt, Director of the Illinois Department of Mental Health and Developmental Disabilities, February 25, 1974.

5. The policies were identified through discussions with Department executives.

6. SB 1655, August 7, 1967, Section 3.1.

7. For a more complete discussion of preventive psychiatry see E. Fuller Torrey, M.D., "The Preventive Road to Psychiatric Fascism," paper delivered at the annual meeting of the American Psychiatric Association, May 8, 1974; Franklin Chu and Sharland Trotter, op. cit., pp. 63-69; David Mechanic, *Mental Health and Social Policy* (Englewood Cliffs: 1969), p.33.

8. Raymond M. Glasscote, James N. Sussex, Elaine Cumming, and Lauren H. Smith, *The Community Mental Health Center,* An Interim Appraisal (Washington, D.C.: 1969), p. 11.

9. Loc. cit., p. 20.

10. Loc. cit., p. 13.

11. Developmental disability includes the mentally retarded and those with cerebral palsy and epilepsy.

12. He had previously reported to the Deputy Director for Clinical Services and Programs.

13. Illinois Department of Mental Health, *A Review of the Fiscal Year 1973 Budget Request,* op. cit.; *Mental Health Statistics for Illinois, Fiscal Year 1973,* op. cit.

14. Illinois Department of Mental Health and Developmental Disabilities, *Funding of Community Mental Health, Developmental Disabilities and Alcoholism Services Guidelines for Grants for Community Programs* (Springfield: November 15, 1973), p. 2.

15. Mechanic, op. cit.

16. Illinois Department of Mental Health, *Mental Health Statistics for Illinois, Fiscal Year 1973,* op. cit., pp. 138-142.

17. Although clearly the high cost of inpatient treatment and care is also a factor.

18. Illinois Department of Mental Health, "The Closure of Peoria State Hospital," unpublished and undated.

19. The label becomes a "Scarlet Letter." See Jim C. Nunnally, Jr., Chapter 18 of *Popular Conceptions of Mental Health,* "An Interpretive Overview," in *Social Psychology and Mental Health,* Henry Wechsler, et al., EDS. (New York: 1970).

20. Glasscote, op. cit., p. 21.

21. Illinois Department of Mental Health, *A Review of the Fiscal Year 1973 Budget Request,* op. cit.

22. Illinois Department of Mental Health and Developmental Disabilities, *Funding of Community Mental Health, Developmental Disabilities and Alcoholism . . .,* op. cit., p. 48.

23. Glasscote, op. cit., p. 22.

24. Merton S. Klause and Kenneth I. Howard, "Program Evaluation in the Public Interest: A New Research Methodology," unpublished paper.

25. See "Dan Walker Speaks Out on a Mental Health Program for the People of Illinois." candidate's position paper; Illinois Mental Health Planning Board, "Mental Health Ombudsman Proposal for Illinois," March 27, 1974.

26. Paper presented to the Senate Democratic Task Force in Response to Testimony by the Illinois Association for the Mentally Retarded, March 1, 1974.

27. Capital Development Board Appropriation Bill SB 1424, Memorandum, Governor's Monthly DMHDD Meeting, July 2, 1974.

28. Defined as those medical personnel (psychiatrists, psychologists, medical doctors) who have not obtained unrestricted licenses to practice their professions in Illinois but have permits only to practice in state mental institutions.

29. Illinois State Legislature, PA 77-2757, amending Chapter 91, Paragraph 142 of the Medical Practices Act.

30. Mechanic, op. cit.

31. Chu and Trotter, op. cit., p. 61

32. Illinois Department of Public Health, *Minimum Standards Rules and Regulations, Long-Term Care Facilities, Sheltered Care, Intermediate Care, Skilled Nursing Care*, Revised July 1973.

33. Interview with Robert Werckle, M.D., Illinois Department of Public Health, March 27, 1974.

CHAPTER THREE

1. It should be emphasized that diagnostic services occur continuously with every offered service. *Diagnostic services* here refers to that service offered to each client when he seeks admission or readmission to the system.

2. During an afternoon's visit to the John Madden Zone Center, the author witnessed the referral of three patients by local police over the course of one-half hour.

3. See Glasscote, et al., op. cit.

4. Illinois Department of Mental Health and Developmental Disabilities. *Guidelines for Clients for Community Programs*, p. 18.

5. Interview with Vladamir Urse, M.D., Chicago Area Department of Mental Health, Chicago Board of Health, April 18, 1974.

6. For the technical research on the debate, see Jane R. Mercer, "The Myth of 3% Prevalence," *Sociobehavioral Studies in Mental Retardation*, Harvey F. Dingman, Ph.D., and George Tarjan, M.D., "Mental Retardation and the Normal Distribution Curve," *American Journal of Mental Deficiency*, Vol. 64, No. 6, May 1960.

7. It should be easier after January 1, 1975, however, when a stronger State Department of Education goes into effect.

8. For example, professionals in the Social and Rehabilitation Service of the U.S. Department of Health, Education, and Welfare (the Federal agency responsible for developmental disability programs) have not given serious attention to what should constitute improvements for clients with different disabilities.

CHAPTER FOUR

1. Raymond M. Glasscote, Michael E. Fishman, Meyer Sonis, *Children and Mental Health Centers* (Washington, D.C.: 1972), p.5.

2. Illinois Department of Mental Health, *Mental Health Statistics for Illinois for FY 1973*, op. cit.

3. Glasscote, Fishman, Meyer, op. cit., p. 4.

4. Ibid,. p. 4.

5. Ibid., pp. 23-24.

6. Illinois Department of Mental Health, *Statement of Policy on Services for Children and Adolescents* (Springfield: 1971), pp. 1-2.

7. Being undertaken by the Governor's Commission for Revision of Mental Health Code of Illinois.

8. Glasscote, Fishman, Meyer, op. cit., p. 39.

9. National Institute for Mental Health, *A Social Work Guide for Long-Term Care Facilities* (Rockville, Maryland: 1974), pp. 27-28.

10. Ibid., p. 28.

11. Illinois Department of Mental Health, *Mental Health Statistics for Illinois for FY 1973*, op. cit.

12. Loc. cit.

13. Loc. cit.

CHAPTER FIVE

1. The Comprehensive State Health Planning Agency, *Planning and Administrative Objectives, The Fiscal Year 1974 Work Program* (Springfield: 1973), pp. 65-76.

CHAPTER SIX

1. Chu and Trotter, op. cit. , pp. 98-99.

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